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# Exploring the Impact of COVID-19 on Adults with Intellectual and Developmental Disabilities in the United States

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# Exploring the Impact of COVID-19 on Adults with Intellectual and Developmental Disabilities in the United States

A dissertation submitted in partial fulfillment for the degree of Doctor of Philosophy at Virginia Commonwealth University

by

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# ABSTRACT

## Exploring the Impact of COVID-19 on Adults with Intellectual and Developmental Disabilities in the United States

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Like most disasters, the COVID-19 pandemic has disproportionately impacted people from historically marginalized communities. People with intellectual and developmental disabilities (IDD) have faced higher rates of infection, hospitalization, and death compared to people without disabilities, as well as significant disruptions to the services that support them to participate in the community. A relative lack of research about the experiences of people with IDD may have contributed to this risk and continues to limit our understanding of the impacts of COVID-19. This three-paper dissertation is guided by the theory of epistemic injustice (Fricker, 2007) to understand the impacts of COVID-19 on people with IDD as they relate to broader questions about whether and to what degree people with IDD are included in research and policy.

Paper one is a scoping review of the literature about the impacts of COVID-19 on people with IDD. Impacts are divided into findings related to physical health (cases, hospitalization, and

death) and psychosocial outcomes (access to services, mental health symptoms, community participation, etc.) and analyzed using the key principles of epistemic injustice. Papers two and three use cross-sectional survey data from a nationally representative sample of people with IDD who use state-funded services. Paper two combines these data with publicly available information about states' responses to the COVID-19 pandemic, COVID-19 case rates, and COVID-19 death rates during the time of survey distribution to identify predictors of being diagnosed with COVID-19. Paper three uses exploratory graph analysis (EGA) to examine differences in similarities in the perceived effects of COVID-19 among survey respondents who answered independently, via proxy, or with a mix of response types.

Findings from paper one suggest that people with IDD experienced high rates of negative physical health and psychosocial outcomes from the COVID-19 pandemic compared to people without disabilities. While none of the identified papers explicitly used the theory of epistemic injustice, I identified instances when examples of injustice related to knowledge appeared in the research. Paper two found that the reported impacts of COVID-19 were similar, but not identical, based on who responded to the survey, with some significant differences between self-, proxy- and mixed-response types. Finally, paper three identified several important predictors of being diagnosed with COVID-19, including both the state and the type of home where people lived.

This dissertation supports prior literature that found that people with IDD have been uniquely and disproportionately impacted by the COVID-19 pandemic compared to people without disabilities and that epistemic injustice in research and policy may have contributed to these inequities. These findings suggest that future research at all levels must include people with IDD to ensure that they are considered in future public health emergencies.

# Chapter 1

# Introduction

## Statement of the Problem

Since the spring of 2020, COVID-19 has had an enormous impact in the United States and around the world. As of February 2023, the United States has had over 100 million confirmed cases of COVID-19 and over one million deaths (Centers for Disease Control and Prevention [CDC], 2023). While the United States is approaching the end of the emergency phase of the pandemic, the impacts of post-COVID conditions (long COVID; CDC, 2022) and of the mental health implications of the pandemic and associated public health responses are still emerging (World Health Organization, 2022).

As with most disasters, the impacts of COVID-19 were not spread evenly across the population. Natural disasters and public health emergencies expose the underlying prejudices and beliefs that shape society (Weibgen, 2014). As such, these disasters disproportionately affect people from historically marginalized communities (Gusmano et al., 2020; Weibgen, 2014).

People with intellectual and developmental disabilities (IDD) have been hit particularly hard by the COVID-19 pandemic. While definitions of IDD vary somewhat based on specific diagnostic criteria, they generally refer to conditions that begin before adulthood and affect both cognitive and adaptive functioning (DD Act; 42 U.S.C. §15001 et seq.; Schalock et al., 2019). In the United States it is estimated that approximately 7.3 million people have an intellectual and/or developmental disability (Larson et al., 2020).

Some research suggests that people with IDD, especially those who live in congregate settings, are at an increased risk of contracting COVID-19 (Gleason et al., 2021; Landes et al., 2020). Evidence also suggests that people with IDD who contract the virus may be at an increased risk of poor outcomes compared with people without disabilities, including hospitalization and death (Gleason et al., 2021; Landes et al., 2020). Beyond these physical health outcomes, many people with IDD also experienced significant disruptions to their support services, which may have contributed to increased feelings of anxiety, stress, and depression (Linehan et al., 2022; Rosencrans et al., 2022).

Despite these risks, people with IDD were largely excluded from or, in some instances, discriminated against in the United State's efforts to respond to the pandemic. The CDC did not release guidance for group homes and other congregate care settings for people with IDD until May 2020, well after evidence emerged that people in these settings were at increased risk from COVID-19 (Landes et al., 2020; Shapiro, 2020). Other official guidance, including state Crisis Standards of Care (CSOC) plans, which provide recommendations for allocating scarce resources in an emergency, explicitly deprioritized people with IDD and other chronic health conditions for life saving care in the event of a shortage of resources (Center for Public Representation [CPR], 2020).

## Theoretical Background

This dissertation will be guided by the theoretical framework of epistemic injustice (Fricker, 2007). Defined as unfairness related to knowledge, epistemic injustice was proposed to understand both the moral and intellectual implications of excluding groups of people from the process of knowledge creation (Fricker, 2007). Specifically, Fricker (2007) describes two categories of epistemic injustice, both of which will be used in this dissertation. Testimonial injustice occurs when a person is not considered a credible witness, even to their own experiences, because of some personal attribute or ties to a marginalized group (Fricker, 2007).

Hermeneutical injustice refers to a gap in the collective knowledge that makes it difficult or impossible for people with marginalized identities to make sense of their own experiences (Fricker, 2007). This gap is rarely accidental but exists because the more powerful groups define what topics are appropriate for research and worthy of being understood (Bhakuni & Abimbola, 2021; Fricker, 2007).

While the theory of epistemic injustice was originally proposed to explain wrongs in interpersonal interactions, it has been expanded and applied to broader structural inequalities (Bhakuni & Abimbola, 2021; Fricker, 2017). This dissertation will build on these efforts, using the theory of epistemic injustice to understand the extent to which people with IDD have been included in research about COVID-19 and in the public health response to the pandemic.

As social workers, we are compelled to respond to both the intellectual and moral harms of epistemic injustice. In both research and practice, we are guided by the principles of social justice and dignity and worth of the person (National Association of Social Workers [NASW], 2021). Within the public health response to COVID-19, social workers may be uniquely situated to advocate for people from marginalized groups, including people with IDD (Felt, 2021). In research, these principles challenge us to find ways to center the voices of people most affected by the issues we seek to understand (Walmsley & Johnson, 2003).

## Introduction to the Dissertation

Guided by the framework of epistemic injustice, each paper in this dissertation will examine the impact of the COVID-19 pandemic on people with IDD from a different angle. Specifically, this dissertation aims to address the ways in which people with IDD have historically been excluded from research and knowledge creation, and the ways in which this absence has manifested during COVID-19.

Paper one will provide an overview of what is known about the impacts of COVID-19 through the frameworks of epistemic injustice (Fricker, 2007) and by Bronfenbrenner's (1979) social ecological model. Specifically, this paper has two main aims:

1) To better understand the impact of the COVID-19 pandemic on people with IDD and
2) To apply Fricker's theory of epistemic injustice to these findings to begin to explain the role of knowledge and power in the ongoing marginalization of this population.

To answer these questions, Paper one will employ a scoping review of the literature on the impacts of COVID-19 on people with IDD, followed by a directed content analysis (Hsieh & Shannon, 2005) using Fricker's (2007) core elements of epistemic injustice as *a priori* codes. Findings are categorized as manifest outcomes–what is known about the experiences of people with IDD in the COVID-19 pandemic, and latent outcomes–the ways in which epistemic injustice can be used to conceptualize these outcomes. These findings are further grouped using Bronfenbrenner's (1979) social ecological model to better understand the impacts of COVID-19 on people with disabilities at the individual, interpersonal, organizational, and societal levels.

Paper two will explore the methodological question of using proxy respondents in survey research with people with IDD. While proxy responses are frequently allowed, especially for people who do not communicate verbally, literature suggests that they may not be valid substitutes for self-report, especially for more subjective and abstract concepts (Claes et al., 2012; Scott & Havercamp, 2018; Tourneir et al., 2020). Beyond issues with validity, testimonial injustice posits that there is moral harm in excluding people from speaking to their own experiences (Fricker, 2007). Against this background, paper two seeks to explore differences and similarities in the perceived impact of COVID-19 based on the type of respondent. Specifically, paper two will answer the following research questions:

1). What are the differences in demographic, disability, and systemic factors between people who respond independently, via proxy, or with a mix of response types?

2). Does the dimensional network structure of COVID-19 impact differ based on whether a participant responds independently, via proxy, or with a mix of both response types?

Data for this study will come from the National Core Indicators In-Person Survey (NCI-IPS) COVID-19 supplement, which contains questions about how participants' lives have changed since the start of the COVID-19 pandemic. Questions in the COVID-19 supplement can be answered either by the participant with IDD or by someone who knows them well; the type of respondent is identified by an item that precedes each question. These items will be used to classify participants into three response types: proxy-report, self-report, and mixed-report. Exploratory graph analysis (EGA; Golino & Espskamp, 2017) will then be used to examine the relationships between variables in the COVID-19 Supplement, focusing on differences and similarities based on the response category.

Literature suggests that the poor health outcomes experienced by people with IDD may be partly attributed to their exclusion from the public health response to COVID-19 (Landes et al., 2020), which may in turn be partly explained by the lack of data about people with IDD (Landes et al., 2020; Landes et al., 2021; Turk et al., 2020). Paper three examines the role of hermeneutical injustice in this exclusion through the following research questions:

1) To what extent did states explicitly protect people with IDD in their COVID-19 response, including emergency response and treatment rationing plans?
2) How did differences in state responses impact reported COVID-19 infection for people with IDD?

Like paper 2, paper 3 will use the NCI-IPS, in combination with publicly available data about states' responses to COVID-19 to investigate the risk of being diagnosed with COVID-19 for people with IDD who use state-funded services. The outcome of interest, COVID-19 diagnosis, will come from the NCI-IPS, as will individual-level predictors. Variables will be clustered at the state-level, as indicated in the NCI-IPS data. State-level predictors will include policies about masking and stay-at-home orders from the first months of the COVID-19 pandemic, state Crisis Standards of Care (CSOC) plans, and COVID-19 case- and death-rates. Individual level predictors, identified from the background section of the NCI-IPS, include demographics, characteristics related to participants' disability, and information about how they live and participate in the community.

As a whole, the three papers of this dissertation seek to apply the tenets of epistemic injustice to an examination of the experiences with IDD during the COVID-19 pandemic. In doing so, this dissertation aims to highlight the need for better data, more inclusive research practices, and more equitable public health policies to support people with IDD.

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on-mental-health-cannot-be-made-light-of#:~:text=A%20great%20number%20of%20people,affected%20much%20more%20than%20others.

# Chapter 2

## Applying a Framework of Epistemic Injustice to Understand the Impact of COVID-19 on People with Intellectual and Developmental Disabilities

Intellectual and developmental disabilities (IDD) refers to a range of conditions that begin before adulthood and affect cognition and adaptive functioning (DD Act; 42 U.S.C. §15001 et seq.; Schalock et al., 2019). Approximately 2.27% of people in the United States have an intellectual and/or developmental disability, totaling about 7.3 million people (Larson et al., 2020). As the COVID-19 pandemic progresses, evidence suggests that people with IDD may be particularly vulnerable compared to the general population. People with IDD may be at increased risk of contracting COVID-19 (Gleason et al., 2021), particularly if they live in congregate settings (Landes et al., 2020). Furthermore, people with IDD who become sick with the virus may be at higher risk of hospitalization (Gleason et al., 2021) and death (Fair Health, 2020; Gleason et al., 2021; Landes et al., 2020; Spreat et al., n.d.).

Despite documented adverse outcomes, people with IDD have been largely overlooked or discriminated against in the United States' response to the pandemic. For example, the CDC did not issue guidance related to group homes for people with IDD until May 2020, more than four months after cases were first reported in the United States, despite evidence that these settings put people at heightened risk for contracting the virus (Landes et al., 2020; Shapiro, 2020). When official guidance was developed, it often discriminated against people with disabilities and chronic health conditions. For example, many state and medical system guidelines stated that people with certain disabilities, support needs, or chronic health conditions should not be prioritized for high-intensity care in the case of a shortage of resources (Center for Public Representation [CPR], 2020a).

In addition to discriminatory treatment allocation systems, people with IDD were rarely prioritized in state vaccination campaigns (Hotez et al, 2021). While people living in congregate care settings, including group homes for people with IDD, and people with some specific conditions, including Down Syndrome, were prioritized early (Hotez et al., 2021), a review conducted in early 2021 found that only 10 states prioritized people with other physical, intellectual, and/or developmental disabilities (Jain et al., 2021). This deprioritization may be partially attributed to the lack of data about health outcomes for people with IDD and other disabilities (Hotez et al., 2021; Wiggins et al., 2021). Fricker's (2007) theory of epistemic injustice, in combination with Bronfenbrenner's (1979) social ecological model can help to identify the marginalization of people with IDD in the COVID-19 pandemic response at the interpersonal, organizational, and societal levels.

## Epistemic Injustice

The theory of epistemic injustice was proposed by Fricker (2007) as unfairness related to knowledge to make sense of "the lived experience of injustice" and the philosophical implications of powerlessness (Fricker, 2017, pp. 8). Specifically, Fricker (2007) divides epistemic injustice into two categories: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when an individual is not considered a credible witness due to some personal characteristic or membership in a marginalized group (Fricker, 2007; Young et al., 2019). In instances of testimonial injustice, prejudice against a person leads them to be viewed as unreliable and less likely to be listened to or believed (Fricker, 2007; Fricker, 2017).

While testimonial injustice describes a situation where stereotypes and assumptions prevent a person from being believed, hermeneutical injustice describes a difficulty in understanding and sharing one's experiences due to a gap in the collective knowledge (Fricker, 2007; Fricker, 2017). Oftentimes, this knowledge gap exists because the experiences of marginalized groups do not fit with existing concepts and are not considered appropriate subjects of research (Bhakuni & Abimbola, 2021; Fricker, 2007). Bhakuni and Abimbola (2021) propose calling this type of wrong "interpretive injustice" to be more accessible to a wider audience.

While the theory of epistemic injustice was initially proposed to explain wrongs in interpersonal interactions, researchers and philosophers have applied the concept to broader, structural inequalities, using micro-level experiences to understand macro-level phenomenon (Bhakuni & Abimbola, 2021; Fricker, 2017). For example, Bhakuni and Abimbola (2021) use the theory of epistemic injustice to critique research practices that excluded local voices from global public health research.

It should be noted that the theory of epistemic injustice has been critiqued by disability researchers. For example, Catala (2020) argues that the original conceptualization of epistemic agency as "the ability to produce, convey, or use knowledge" is too narrowly defined and excludes many people with IDD and other cognitive impairments (p. 756). Specifically, Catala (2020) points out that Fricker's (2007) use of 'speaker' and 'hearer' to designate roles in the communication process centers speech and ignores people who do not communicate using spoken language. Similarly, epistemic injustice overly emphasizes propositional knowledge and reasoning above other ways of knowing (Catala, 2020). Despite these criticisms, epistemic injustice is a useful framework for exploring the experiences of people with IDD during the COVID-19 pandemic specifically and health disparities more broadly by explicitly naming the intellectual and moral wrongs that place people with IDD at heightened risk (Fricker, 2007).

For this paper, understanding the relationship between epistemic injustice and health is especially important. Medical providers are epistemically privileged and considered to be experts by virtue of their training and social position (Carel & Kidd, 2014; Peña-Guzmán and Reynolds, 2019). While this privilege is clearly merited in clinical decision making, it can come at the expense of patients' own expertise (Carel & Kidd, 2014; Iezzoni et al., 2021; Peña-Guzmán and Reynolds, 2019). For instance, epistemic injustice at medical appointments means that patients, particularly those with chronic illnesses, psychiatric conditions, or disabilities, are frequently ignored as unreliable, even when describing their own experiences, impeding effective communication (Carel & Kidd, 2014; Iezzoni et al., 2021; Peña-Guzmán and Reynolds, 2019). In contrast, Carel and Kidd (2014) argue that epistemic justice in healthcare would respect the diverse epistemic privileges of patients and providers, where providers are the experts in clinical assessments and diagnostics and patients are the experts in their own experiences.

The harms of testimonial injustice in interactions between healthcare providers and patients can be compounded by hermeneutical injustice. Research suggests that many providers have insufficient knowledge of intellectual disabilities and associated health conditions, due in part to a lack of formal education about disabilities and in part to a lack of exposure to this population (Krahn et al., 2006; Pelleboer-Gunnink et al., 2017; Wilkinson et al., 2012). In the absence of needed information, providers may rely on stereotyped assumptions of patients with IDD (Krahn et al., 2006; Pelleboer-Gunnink et al., 2017; Wilkinson et al., 2012).

Beyond the epistemic harm of being ignored and excluded, epistemic injustice in medicine can have dire consequences for patients' health (Carel & Kidd, 2013; Iezzoni et al., 2021; Peña-Guzmán & Reynolds, 2019). Diagnostic overshadowing is a well-documented example of the negative impact of testimonial injustice among doctors treating patients with IDD, wherein symptoms and behaviors are ascribed to the disability, rather than to an unrelated medical condition (Peña-Guzmán & Reynolds, 2019; While & Clarke, 2010). In these situations, a provider’s overreliance on their own stereotyped beliefs about disability can delay treatment for physical health conditions (Carel & Kidd, 2014; Peña-Guzmán & Reynolds, 2019; While & Clarke, 2010).

The theory of epistemic injustice has also been used to identify injustices in academic global health research. Bhakuni and Abimbola (2021) argue that academic researchers have historically excluded local experts from the process of knowledge creation. Again, this injustice has both epistemic and practical implications. From a strictly epistemic perspective, local researchers and practitioners are denied the opportunity to generate knowledge (Bhakuni & Abimbola, 2021). From a practical and moral perspective, excluding local experts may lead to prejudicial assumptions and ineffective interventions that perpetuate existing health inequities (Bhakuni & Abimbola, 2021).

## Social Construction of Intellectual Disability

In her examination of epistemic injustice, Fricker (2007) emphasizes the importance of understanding the cultural and historical settings, social constructions, and prejudices of a group in order to identify and correct for biases and gaps in knowledge. Before we can apply Fricker’s theory to an examination of the existing research on the impacts of the COVID-19 pandemic, we must first understand the historic, social, and structural factors that have shaped the concept of intellectual disability in the United States.

From at least the 18th century, people with IDD have been considered less worthy of study and care than people without disabilities, making them particularly vulnerable to a public health crisis like the COVID-19 pandemic (see Abbas, 2016; Goodey, 2001; Siebers, 2008; Trent, 2017). As Fricker (2007) points out, negative stereotypes do not need to be believed to have an impact. Instead, these innate biases “more surreptitiously” discredit marginalized groups and work to maintain the existing societal power structures (Fricker, 2007, pp. 98). While attitudes and policies towards people with IDD have shifted dramatically since the 1970s (Wehmeyer & Schalock, 2013), historical prejudices and models of disability continue to inform policy and practices today (Guevara, 2021).

### Study Aims

This study has two main aims. First, given the rapidly evolving nature of COVID-19 and the lack of research centering people with IDD, it seeks to better understand the impact of the pandemic on people with IDD through a scoping review of the literature. Second, it applies Fricker's theory of epistemic injustice to these findings to begin to explain the role of knowledge and power in the ongoing marginalization of this population.

## Methods

This study was conducted in two stages. First, I conducted a scoping review to better understand the impacts of this pandemic on the physical health, mental health, and psychosocial outcomes of people with IDD. I then analyzed the identified articles using Fricker's (2007) framework of epistemic injustice to explain the marginalization and disproportionate impact of the pandemic on this population.

The search was conducted in April 2022 for articles published in 2020 through 2022. Articles were identified through a search of Academic Search Complete, PubMed, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases using the search terms "intellectual disability OR developmental disability" AND "covid-19 or coronavirus or 2019-ncov or sars-cov-2 or cov-19" AND "prognosis OR outcome OR incidence OR fatality". The reference lists of articles that met inclusion and exclusion criteria (described below) were reviewed for additional studies. Finally, the "cited by" feature of Google Scholar was used to identify recent articles citing any included article. Google Scholar was needed to identify articles that had not yet been indexed in the databases used in this search.

### Inclusion and Exclusion Criteria

Articles were included if they were published in English in a peer-reviewed journal and described the outcomes of people with IDD in the United States during the COVID-19 pandemic. International studies that included a US sample were included in article selection, but data extraction and analysis only considered results from the United States. Given the rapidly changing landscape and the relative paucity of research in this field, “outcome” was interpreted broadly and included health (case rates, hospitalization, fatality, etc.) as well as mental health and psychosocial impacts. Articles that only described changes to the service system were not included. I excluded gray literature, including dissertations, theses, conference proceedings, and articles that appeared in sources that were not peer reviewed. I also excluded articles that did not have empirical findings, such as reviews or theoretical pieces. Finally, case studies of only one individual were excluded.

### Data Analysis Approach

Data extraction and analysis followed guidelines for directed content analysis suggested by Hseih and Shannon (2005). Hseih and Shannon (2005) suggest that a directed content analysis approach is appropriate when a theory exists but needs additional exploration or description. As epistemic injustice has been well defined as a theory but has not been applied to the health inequities of people with IDD, directed content analysis was deemed appropriate for this study. Consistent with this analytical approach, codes were determined and defined *a priori* based on existing research on health equity for people with IDD and on Fricker’s (2007) core elements of epistemic injustice. These codes and definitions are presented in Table 1.

### Data Extraction and Analysis

After an initial full review of each article to identify research questions, methods, and main findings, data segments were extracted into three broad categories: methods and research questions, results, and discussions. I first highlighted segments that represented manifest findings related to the impact of COVID-19 and segments that reflected the influence of epistemic injustice, as suggested by Hsieh and Shannon (2005). These highlighted sections were then coded using the codes identified previously.

## Results

### Included Articles

Searches of the three initial databases yielded 197 articles after excluding duplicates. Fifteen articles remained after screening the titles and abstracts for eligibility based on the above criteria; five of these articles were excluded after a full-text review because they contained only case studies of individuals or service organizations (N = 3) or did not focus on people with IDD (N=1). One article (Doody & Keenan, 2021) was excluded because it was a scoping review and did not provide detailed enough results for data analysis. A hand search of reference lists yielded one additional article that met inclusion criteria. Finally, the Google Scholar “cited by" search yielded five articles. In total, 16 articles were retained for content analysis, published between July 2020 and April 2022.

Of the 16 studies included in the final analysis, only one used qualitative methods to understand the experiences of people with IDD during the COVID-19 pandemic (Carey et al., 2021). Three studies utilized surveys of adults with IDD that allowed for proxy-responses to some or all questions (Fisher et al., 2022; Friedman, 2021; Rosencrans et al., 2021), and two studies only surveyed caregivers (family members and paid staff; Hartley et al., 2022; Linehan et al., 2022). The remaining 10 studies used secondary data analysis (Davis et al., 2021; Gleason et al., 2021; Karpur et al., 2021; Koyama et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al., 2021b; Landes et al., 2021c; Malle et al., 2021; Turk et al., 2020). Included articles are presented in Table 2.

## Outcomes

Results are presented in two sections–the manifest findings that describe the impact of COVID-19 on physical health, mental health, and psychosocial factors for people with IDD and latent factors, which explicitly apply a framework of epistemic injustice to these findings.

### *Manifest Findings*

**COVID-19 Related Hospitalization and Mortality.** Poor physical health outcomes for people with IDD were documented in 10 of the articles identified in the scoping review (Davis et al., 2021; Gleason et al., 2021; Karpur et al., 2021; Koyoma et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al, 2021b; Landes et al., 2021c; Malles et al., 2021; Turk et al., 2020). Of the studies that examined physical health outcomes, four studies reported that people with IDD were more likely to be hospitalized, have longer hospital stays, and/or be admitted to the ICU compared to patients without IDD (Gleason et al., 2021; Karpur et al., 2021; Koyoma et al., 2022; Malles et al., 2021). Additionally, seven studies reported a higher mortality or case-fatality rate from COVID-19 for patients with IDD (Davis et al., 2021; Gleason et al., 2021; Koyoma et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al, 2021b; Malles et al., 2021). One study (Turk et al., 2020) found that the overall case fatality rate was similar between patients with and without IDD, but that people with IDD who died from COVID-19 tended to be younger than people without IDD.

**Mental Health and Psychosocial Outcomes.** Six of the included studies reported on mental health and/or psychosocial outcomes for people with IDD during the COVID-19 pandemic (Carey et al., 2022; Fisher et al., 2022; Friedman, 2021; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2021). Overall, these articles reported negative outcomes from the COVID-19 pandemic. Studies suggest that participants were more worried, stressed, or anxious during COVID-19 than before the pandemic (Carey et al., 2022; Fisher et al., 2022; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2022). Studies also reported high rates of changes in the daily lives of people with IDD due to COVID-19 and the public health response, including changes to employment or day programs (Carey et al., 2021; Fisher et al., 2022; Hartley et al., 2022), social activities (Carey et al., 2021; Friedman, 2021), residence, support staff, and disability services (Hartley et al., 20220; Linehan et al., 2022), and access to healthcare (Linehan et al., 2022; Rosencrans et al., 2021).

### ***Latent Findings***

Unsurprisingly, no articles explicitly referenced epistemic injustice in their analyses of the impacts of COVID-19 on people with IDD. However, instances of testimonial and hermeneutical injustice can be applied to findings in this scoping review.

**Testimonial Injustice.** *Testimonial injustice* is most seen in an examination of the research methods in this scoping review of the literature. As described previously, only one study used qualitative methods with participants with IDD (Carey et al., 2022), while 10 studies used secondary data analysis (Davis et al., 2021; Gleason et al., 2021; Karpur et al., 2021; Koyama et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al., 2021b; Landes et al., 2021c; Malle et al., 2021; Turk et al., 2020). Secondary data analysis is a key tool for public health research, but the preponderance of secondary data at the exclusion of studies actively involving people with IDD suggests the possibility of *epistemic objectification* in research about COVID-19 and people with IDD. In epistemic objectification, a person or group is treated as a "mere object" rather than an active participant in knowledge creation, amounting "to a sort of dehumanization" (Fricker, 2007; pp. 133).

Fricker (2007) is also clear that exclusion does not have to be explicit to constitute testimonial injustice. Instead, marginalized social groups "tend simply not to be asked to share their thoughts" on issues that concern them (Fricker, 2007, pp. 130). In this review, two articles (Hartley et al., 2022; Linehan et al., 2022) only surveyed caregivers of people with IDD, rather than soliciting opinions directly. This finding is particularly noteworthy as both articles reported subjective impacts of COVID-19, including increased feelings of anxiety.

These injustices were balanced by several clear examples of *testimonial justice* in the identified research methods. Carey et al. (2021) and Rosencrans et al. (2021) state that materials were written in plain language and checked for accessibility prior to beginning the study. Rosencrans et al., (2021) also described the process by which proxy responses were allowed, specifying that questions were designed to be read aloud by a "helper" who supported the respondent with IDD.

Carey et al (2022) is an excellent example of how people with IDD can be centered in the research process. Researchers in this study developed focus group questions based on previous literature on health inequities and COVID-19, ensuring that questions were written in a way that participants would easily understand (Carey et al., 2022). An expert panel reviewed these questions for reading level and for comprehensiveness, leading researchers to add an additional category of questions (Carey et al., 2022). Focus groups were then held over Zoom, with researchers present to troubleshoot any technological issues that impeded full participation (Carey et al., 2022).

**Hermeneutical Injustice.** Several examples of hermeneutical injustice can also be seen in this review. Multiple authors describe a *situated hermeneutical inequality* wherein a gap in the collective knowledge, in this case a lack of robust data about COVID-19 or general health outcomes for people with IDD, disproportionately impacts a particular group by hampering research and interventions (Fricker, 2007). Specifically, Friedman (2021), Landes et al., 2020, Landes et al., 2021a, and Turk et al., 2020 all described inadequate surveillance of COVID-19 in people with IDD, particularly for people who lived in congregate settings. Gleason et al. 2021 and Karpur et al., 2021 used electronic health records in their research and reported that inaccurate or missing diagnostic codes limited their research. Finally, Linehan et al., 2022 described people with IDD are often excluded from large, population-based health surveys, contributing to the poor understanding of health outcomes for this population.

Landes and colleagues (2021b) suggest that the lack of robust information about health outcomes for people with IDD before and during the COVID-19 pandemic limited the public health response for this population. For example, while many states prioritized people with IDD who lived in congregate settings in their vaccine rollout, many did not include people with IDD who lived in non-congregate settings (Landes et al., 2021b). Landes and colleagues (2021b) propose that this exclusion may have been due in part to a lack of data about the impact of COVID-19 on people with IDD who live in the community. The situated hermeneutical inequality, wherein very little robust public health data exists for people with IDD, contributed to an exacerbation of existing inequities, further marginalizing this population.

Authors also suggest that people with IDD may have been excluded from the public health response to COVID-19 because of *hermeneutical marginalization*, where the interpretation of a particular issue is based on the experiences of more hermeneutically powerful groups, rather than the group most directly impacted (Fricker, 2007). For example, Landes (2020) argues that the public health officials who determine COVID-19 policies do so without a robust understanding about group homes for people with IDD. This example clearly highlights how the hermeneutical marginalization of a group can directly translate to policy decisions that exacerbate inequities–public health officials do not understand how group homes work and so implement policies that put people with IDD at increased risk (Landes, 2020).

## Discussion

This scoping review of the literature supports the claim that people with IDD faced significant difficulties during the first two years of the COVID-19 pandemic and highlights the ways in which epistemic injustice, as described by Fricker (2007) may be shaping research and the ways in which people with IDD are considered in the COVID-19 pandemic response in the United States. The relationships between the manifest and latent findings of this review are presented in Figure 1. This model draws from the social ecological model proposed by Bronfenbrenner (1977) and centers individual-level manifest findings in the innermost of a series of nested circles. Testimonial injustice is situated in the next circle, indicating the ways in which interpersonal interactions in data collection or in healthcare settings may influence these outcomes. Finally, hermeneutical injustice is depicted in the outermost circle, representing how the systemic exclusion of people with IDD from research and policy impacts both interpersonal relationships and individual-level outcomes.

### Individual Level: Manifest Findings

In terms of physical health outcomes, people with IDD were more likely than people without IDD to be hospitalized or die from COVID-19 and, in some cases, were also more likely to contract the virus (Davis et al., 2021; Gleason et al., 2021; Karpur et al., 2021; Koyoma et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al, 2021b; Landes et al., 2021c; Malles et al., 2021; Turk et al., 2020). Additionally, people with IDD faced disruptions to services, employment, and community integration due to COVID-19 and the public health response (Carey et al., 2022; Fisher et al., 2022; Friedman, 2021; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2021). Several studies suggested that people with IDD have higher rates of anxiety, stress, and depression (Carey et al., 2022; Fisher et al., 2022; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2022) than they did before the COVID-19 pandemic. These findings make claims that people with IDD were excluded from the COVID-19 response in the United States particularly concerning (CPR, 2020a; Hotez, 2021; Jain et al., 2021; Landes, 2020; Wiggins et al., 2021).

### Interpersonal Level: Testimonial Injustice

Testimonial injustice is clearly seen in the reliance on secondary data and proxy reporters in the studies identified in this review, which suggests that epistemic injustice may be built into prevailing research methods for learning about people with IDD. As stated previously, negative stereotypes about people or groups do not need to be believed by researchers to influence the ways they conduct research (Fricker, 2007). The studies identified in this review highlight the ongoing challenges in conducting research with people with IDD; only one study explicitly centered the lived experiences of people with IDD (Carey et al., 2022).

Some projects that include people with IDD as participants or co-researchers are not approved by university ethics committees because of assumptions about capacity and disability

(Stack & McDonald, 2014). Once projects are approved, creating accessible research materials is time consuming and costly (Stack & McDonald, 2014), particularly for participants who do not read or communicate verbally (Scott & Havercamp, 2018). Taken as a whole, this combination of practical challenges and negative stereotypes about people with IDD seems to have limited opportunities for research with this population. A random survey of clinical trials found that only 2% of studies included participants with intellectual disabilities (Feldman et al., 2014).

Carey and colleagues (2022) offer both practical guidance for promoting testimonial injustice in research with people with IDD and demonstrate the benefits of doing so. In developing questions for their focus groups, researchers integrated both existing literature and the perspectives of experts in the field to ensure that questions were easily understood and captured the full range of experiences (Carey et al., 2022). Additionally, researchers met with participants to explain the study verbally prior to the focus groups and were on hand to provide practical support during the focus groups to support full participation (Carey et al., 2022). In intentionally balancing established academic knowledge with the lived experiences of research participants, Carey and colleagues (2022) captured nuanced details about the impact of COVID-19 on the lives of people with IDD. The researchers note that all participants in their study had previously participated in training on self-advocacy and the use of technology, suggesting that including people with IDD in the research process may be a long-term project (Carey et al., 2022).

Beyond research, testimonial injustice in interactions between healthcare providers and patients with IDD may be related to the high rates of hospitalization and death reported in this review. Prior to the COVID-19 pandemic, research suggested that testimonial injustice based on negative social constructions lead medical providers to rate patients with disabilities as having a lower quality of life than patients without disabilities (Albrecht & Devlieger, 1999; Iezzoni et al., 2021; Peña-Guzmán and Reynolds, 2019). This example of testimonial injustice reinforces the existing power structure wherein healthcare providers are believed and patients with disabilities are denied the opportunity to act as experts in their own lives and experiences (Albrecht & Devlieger, 1999; Iezzoni et al., 2021; Peña-Guzmán & Reynolds, 2019) and is particularly impactful in the context of understanding impacts of the COVID-19 pandemic on people with IDD. While the United States Department of Health and Human Services Office for Civil Rights (OCR) explicitly forbade treatment rationing protocols based on subjective measures of quality of life, research from before the COVID-19 pandemic suggests that healthcare providers might not be aware of their own biases in decision making (Peña-Guzmán & Reynolds, 2019).

### Societal Level: Hermeneutical Injustice

While testimonial justice denies patients with IDD agency in healthcare settings, hermeneutical injustice, or an exclusion from the process of knowledge creation for members of less powerful groups, perpetuates this exclusion on a broader scale. Research on health outcomes for people with IDD is limited by a lack of data (Havercamp et al., 2019; Krahn, 2019). Several studies noted that their own research was limited by a lack of robust data about health outcomes for people with IDD prior to and during the COVID-19 pandemic (Friedman, 2021; Gleason et al., 2021; Karpur et al., 2021; Landes et al., 2021a; Landes et al., 2020; Turk et al., 2020).

This lack of data was noted by researchers prior to the COVID-19 pandemic (Havercamp et al., 2019; Krahn et al., 2019). Many population-level surveys make it impossible to identify people with IDD because they lack disability identifiers, use broad language that does not distinguish between conditions like intellectual disability, developmental disability, dementia, and traumatic brain injury, or do not include people with IDD in their sampling frames

(Havercamp et al., 2019; Krahn, 2019). One study suggested that national health surveillance surveys only identify about 60% of adults with IDD who live in the community (Magana et al., 2016). Again, these existing injustices were exacerbated during the COVID-19 pandemic, further disadvantaging an already marginalized group. This exclusion from existing population-level research may have contributed to people with IDD being largely left out of the COVID-19 response in the United States (Hotez et al., 2021).

Instruments designed as objective measures of health are also influenced by socially-constructed beliefs about disability and health. For example, Festen and colleagues (2021) report that frailty is commonly used as a criterion in determining which patients receive intensive care in a shortage. One commonly used measure, the Clinical Frailty Scale (CFS), relies primarily on a patient's ability to independently perform activities of daily living and has not been validated in patients with IDD (Festen et al., 2021). Festen and colleagues (2021) found that nearly three-quarters of patients with IDD would have been incorrectly classified as being potentially too frail to benefit from intensive treatment when assessed using the CFS as opposed to a measure designed for patients with IDD (Festen et al., 2021). While reliable and valid measures are necessary for quality care at any time, these tools are vital in the context of treatment rationing protocols necessitated by the COVID-19 pandemic, in which patient frailty was often used to prioritize care (Festen et al., 2021).

## Implications

This scoping review of the literature on the impacts of COVID-19 on people with IDD supports Fricker's (2007) claim that epistemic injustice is both a moral and an intellectual virtue, serving "equally both justice and truth" (pp 121). Achieving epistemic justice and, in the context of the COVID-19, equitable health outcomes, requires those with power to critically challenge the prejudices and stereotypes they hold against less powerful groups and the ways that these beliefs have shaped policy and practice. As the United States moves into the endemic phase of the COVID-19 pandemic, confronting the underlying injustices in the response so far has important implications for research, practice, and policy.

The first step to confronting epistemic injustice is to make people aware of its impacts (Fricker, 2007). When people are silenced–in the doctor's office or in the data–the status quo continues unchallenged (Fricker, 2007). Developing robust and inclusive research methods that capture the needs and experiences of people with IDD is essential to promoting health equity. Researchers have suggested a number of practices to improve research for and with people with IDD including using merged datasets, high quality psychometrics, and advanced statistical analyses (Bogenschutz et al., 2022).

Beyond the lack of information, what research about health outcomes for people with IDD does exist rarely centers the experiences and needs of people with IDD and their families (Hotez et al., 2021). Truly inclusive and epistemically just research involves people with IDD at all stages of the research process, as active agents in the creation and dissemination of knowledge (Fricker, 2007; Walmsley & Johnson, 2003; Strnadova & Walmsley, 2018).

## Limitations

As with any study, this review has several limitations that should be noted. The literature review took place at one point in time (April 2022) in the midst of a rapidly evolving global pandemic and public health response. While the spring of 2022 was a relatively stable moment in the COVID-19 pandemic in the United States, when all but the youngest children were eligible for the vaccine and between surges from Omicron variants, any information must be taken in the context of a constantly evolving situation. Statements that were true in 2020, when COVID-19 was first identified, may not hold over time.

Furthermore, the lack of a coordinated federal response to COVID-19 limited state responses to the virus and the generalizability of this review. Of the studies that used secondary data to examine the health impacts of COVID-19 on people with IDD, six used data from specific geographic regions (Davis et al., 2021; Landes et al., 2020; Landes et al., 2021a; Landes et al., 2021b; Landes et al., 2021c; Malle et al., 2021). Given the wide variation in the spread of COVID-19 in the United States and in different states' responses to the virus, findings from these studies may not be generalizable to the US as a whole.

## Conclusion

Considering the needs of people with IDD, other disabilities, and chronic health conditions remains important as the United States exits the acute phase of the COVID-19 pandemic and relaxes public health measures. Applying the framework of epistemic justice, addressing these inequitable policies means continuing to amplify the voices of people with disabilities.

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# Tables and Figures

**Table 1.** Directed Content Review Codes

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**Manifest Codes: COVID-19 Impact**

Hospitalization and Mortality: findings related to COVID-19 case rates, treatment, hospitalization, intensive care/intubation, death

Mental Health: findings related to official mental health diagnoses (depression, anxiety, bipolar, etc.) and reported symptoms of mental illness

Psychosocial: findings related to disruption in daily lives of people with IDD

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**Latent Codes: Epistemic Injustice**

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**Testimonial Injustice: the injustice that a speaker suffers in receiving deflated credibility from the hearer owing to identity prejudice on the hearer's part**

Identity power: "a form of social power which is directly dependent upon shared social-imaginative conceptions of the social identities of those implicated in the particular operation of power"

Identity prejudice: "prejudices against people *qua* social type"

Testimonial sensibility: "a form of rational sensitivity that is socially inculcated and trained by countless experiences of testimonial exchange, individual and collective"

Testimonial justice: "a virtue such that the influence of identity prejudice on the hearer's credibility judgment is detected and corrected for"

Epistemic objectification: "the subject is wrongfully excluded from the community of trusted informants, and this means he is unable to be a participant in the sharing of knowledge (except in so far as he might be made use of as an object of knowledge through others using him as a source of information). He is thus demoted from subject to object…"

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**Hermeneutical injustice: "a gap in our shared tools of social interpretation–where is is no accident that the cognitive disadvantage created by this gap impinges unequally on different social groups"**

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Hermeneutical marginalization: marginalized groups "participate unequally in the practices through which social meanings are generated; collective forms of understanding are rendered structurally prejudicial in respect of content and/or style: the social experiences of members of hermetically marginalized groups are left inadequately conceptualized and so ill-understood…"

Situated hermeneutical inequality: "social situation is such that a collective hermeneutical gap prevents them in particular from making sense of an experience which it is strongly in their interests to render intelligible"

Hermeneutical justice: "hearer exercises a reflexive critical sensitivity to any reduced intelligibility incurred by the speaker owing to a gap in collective hermeneutical resources."

**Table 2.** Articles Included in the Scoping Review

| Citation | Research Question/Aim | Methods | Findings |
|---|---|---|---|
| Carey, G. C., Joseph, B., & Finnegan, L. A. (2021). Effects of the COVID-19 pandemic on college students with intellectual disabilities. Journal of Vocational Rehabilitation, (Preprint), 1-11. 10.3233/JVR-211162 | To capture and analyze adults' lived experiences with ID during the COVID-19 pandemic. | Focus groups of graduates and currently-enrolled post secondary education students. N = 9 | Four themes (employment, daily living, social, well-being) and eleven subthemes emerged during the interviews. Participants described the impact of COVID-19, such as learning, and implementing new procedures in the workplace, taking on increased responsibilities at home, and the uncertainty of their future. |
| Davis, M. D., Spreat, S., Cox, R., Holder, M., Burke, K. M., & Martin, D. M. (2021). COVID-19 mortality rates for persons with intellectual and developmental disabilities. | To examine of the impact of COVID-19 on the health of people with IDD at both early (May 2020) and later points (January 2021) in the pandemic to examine how early trends related to infection and fatality rates have changed over time. | Data on infection and mortality obtained from IDD organizations in California, Colorado, Indiana, Maryland, New Jersey, New York, Pennsylvania, and Virginia and from Johns Hopkins from May 2020 and January 2021 | The infection rate in May 2021 was lower for adults with IDD than for the general population (.74). Fatality rates declined overall, but people with IDD remained twice as likely to die from COVID-19 (2.29) |
| Fisher, M. H., Sung, C., Kammes, R. R., Okyere, C., & Park, J. (2022). Social support as a mediator of stress and life satisfaction for people with intellectual or developmental disabilities during the COVID-19 pandemic. Journal of Applied Research in Intellectual Disabilities, 35(1), 243-251. | To examine factors that predict stress level and life satisfaction among adults with intellectual or developmental disabilities during the COVID-19 pandemic and the role of social support. | Online survey of adults with and without disabilities, N = 2028, 181 with IDD (or proxy) | 92.8% of respondents reported negative impact of the pandemic. Negative impact was related to stress level; social support reduced stress. Stress level and the negative impact of the pandemic were inversely related to life satisfaction; social support was positively related to life satisfaction. Social support partially mediated the association between stress level and life satisfaction. |
| Friedman, C. (2021). The COVID-19 pandemic and quality of life outcomes of people with intellectual and developmental disabilities. Disability | To explore the impact of the COVID-19 pandemic on the | We conducted a secondary analysis of Personal Outcome | There were significant differences in the following quality of life outcomes of PWIDD |

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| and Health Journal, 14(4), 101117. 10.1016/j.dhjo.2021.101117 | quality of life outcomes of PWIDD. | Measures® interviews from 2019 to 2020 (n = 2284). | between 2019 and 2020: continuity and security; interact with other members of the community; participate in the life of the community; intimate relationships; and, choose goals. |
| Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. NEJM Catalyst Innovations in Care Delivery, 2(2). | To understand the risk of contracting COVID-19, being admitted to the hospital, and being admitted to the ICU for people with IDD. | Cross sectional study of 547 health care providers (467,773 patients) with COVID diagnosis from April 2020 to August 2020. | This study found that those with developmental disabilities were over 3 times as likely to die following a diagnosis of Covid-19 and that those with intellectual disabilities were 2.75 times as likely to die following such a diagnosis, |
| Hartley, S. L., Fleming, V., Piro-Gambetti, B., Cohen, A., Ances, B. M., Yassa, M. A., ... & Schupf, N. (2022). Impact of the COVID 19 pandemic on daily life, mood, and behavior of adults with Down syndrome. Disability and Health Journal, 101278. | To understand how the COVID-19 pandemic has altered daily life (including residence, employment, and participation in adult disability day programs) and influenced the mood and behavior of adults with Down syndrome. | Online or telephone survey of caregivers of adults with DS (n=171) in US and UK | The residence of 17% of individuals was altered, and 89% of those who had been employed stopped working during the pandemic. One-third (33%) of individuals were reported to be more irritable or easily angered, 52% were reported to be more anxious, and 41% were reported to be more sad/depressed/unhappy relative to prepandemic. |
| Karpur, A., Vasudevan, V., Shih, A., & Frazier, T. (2021). Brief report: impact of COVID-19 in individuals with autism spectrum disorders: analysis of a National Private Claims Insurance database. Journal of autism and developmental disorders, 1-7. | To illustrate the impact of COVID-19 infection on the health of individuals with ASD when compared to their peers with other chronic conditions. | Fair Health National Private Insurance Claims database Feb 1 2020 through Sep 30 2020. N = 35,898,076 | Individuals with ASD + ID were nine times more likely to be hospitalized following COVID-19 infection and were nearly six times more likely to have an elevated length of hospital stay compared to those without ASD + ID. |
| Koyama, A. K., Koumans, E. H., Sircar, K., Lavery, A., Hsu, J., Ryerson, A. B., & Siegel, D. A. (2022). Severe Outcomes, Readmission, and Length of Stay Among COVID-19 Patients with Intellectual and Developmental Disabilities. International Journal of Infectious Diseases. 10.1016/j.ijid.2022.01.038 | To evaluate the association between intellectual and developmental disabilities (IDDs) and severe COVID-19 outcomes, 30-day readmission, and/or increased length of stay | Data from 900 hospitals from Premier Healthcare Database Special COVID-19 release. COVID-19 discharge data March 1 2020 through June 30 2021; n=643,765. | Patients with any IDD were at a significantly greater risk of at least 1 severe outcome, 30-day readmission, or longer LOS than patients without any IDD. Compared with those without any IDD, patients with Down syndrome had the greatest |

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| | (LOS) using a large electronic administrative database. | | odds of ICU admission (odds ratio [OR] and 95% confidence interval [CI]: 1.96 [1.73-2.21]), IMV (OR: 2.37 [2.07-2.70]), and mortality (OR: 2.33 [2.00-2.73]). Patients with ASD and those with Down syndrome both had over a 40% longer mean LOS. Patients with intellectual disabilities had a 23% (12-35%) increased odds of 30-day readmission. |
| Landes, S. D., Turk, M. A., & Ervin, D. A. (2021). COVID-19 case-fatality disparities among people with intellectual and developmental disabilities: Evidence from 12 US jurisdictions. Disability and Health Journal, 14(4), 101116. 10.1016/j.dhjo.2021.101116 | This study compared COVID-19 case-fatality rates among people with IDD in 11 states and the District of Columbia that are publicly reporting data. | Publicly reported data on COVID-19 outcomes (cumulative cases and deaths) among people with IDD March 31 - April 13 2021 from 12 jurisdictions, compared to Johns' Hopkins data. | Comparison of case-fatality rates between people with IDD and their respective jurisdiction populations demonstrates that case-fatality rates were consistently higher for people with IDD living in congregate residential settings (fifteen instances) and receiving 24/7 nursing services (two instances). Results were mixed for people with IDD living in their own or a family home (eight instances). |
| Landes, S. D., Turk, M. A., & Wong, A. W. (2021). COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. Disability and Health Journal, 14(2), 101051. 10.1016/j.dhjo.2020.101051 | To determine the impact of residential setting and level of skilled nursing care on COVID-19 outcomes for people receiving IDD services, compared to those not receiving IDD services. | Data from California department of DDS compared with data from California Open Data Portal, as of May 2020 | Compared to Californians not receiving IDD services, in general, those receiving IDD services had a 60% lower case rate, but 2.8 times higher case-fatality rate. COVID-19 outcomes varied significantly among Californians receiving IDD services by type of residence and skilled nursing care needs: higher rates of diagnosis in settings with larger number of residents, higher case-fatality and mortality rates in settings that provided 24-h skilled nursing care. |

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| Landes, S. D., Turk, M. A., Damiani, M. R., Proctor, P., & Baier, S. (2021). Risk factors associated with COVID-19 outcomes among people with intellectual and developmental disabilities receiving residential services. JAMA network open, 4(6), e2112862-e2112862. 10.1001/jamanetworkopen.2021.12862 | What individual and residential characteristics are associated with COVID-19 outcomes for people with intellectual and developmental disabilities receiving residential services? | Cohort study of 543 people with IDD receiving residential services in NY from March 1 to October 1 2020. Data obtained through case files | Age, larger residential settings, Down syndrome, and chronic kidney disease were associated with COVID-19 diagnosis. Heart disease was associated with COVID-19 mortality |
| Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. Disability and Health Journal, 13(4), 100969. 10.1016/j.dhjo.2020.100969 | To describe COVID-19 outcomes among people with IDD living in residential groups homes in the state of New York and the general population of New York State. | Data from 115 service providers in New York from January to May 28, 2020, including case rates, fatality, and mortality. Data from NY from state and city health departments. | People with IDD in residential settings had higher case rates, fatality rates, and mortality rates compared to the general population. |
| Linehan, C., Birkbeck, G., Araten-Bergman, T., Baumbusch, J., Beadle-Brown, J., Bigby, C., ... & Tossebro, J. (2022). COVID-19 IDD: Findings from a global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities (IDD) and their caregivers. HRB Open Research, 5, 27. | What are family members' and paid staff's perceptions of the impact of the COVID-19 pandemic on individuals with IDD and their caregivers? Do differences exist in the self-reported experiences of those supporting individuals living in different living arrangements and in different international jurisdictions? | International online survey of family members, paid staff, and case managers (n = 3,754). | Caregivers observed increases in depression/anxiety, stereotyped behaviours, aggression towards others and weight gain in the person(s) they supported. They also reported difficulties supporting the person(s) to access healthcare. Families reported reducing or ceasing employment and absorbed additional costs when supporting their family member. Direct support professionals experienced changes in staff shifts, staff absences, increased workload and hiring of casual staff. Caregivers' wellbeing revealed high levels of stress, depression, and less so anxiety. |
| Malle, L., Gao, C., Hur, C., Truong, H. Q., Bouvier, N. M., Percha, B., ... & Bogunovic, D. (2021). Individuals with Down syndrome hospitalized with COVID-19 have more severe disease. Genetics in Medicine, 23(3), | To conduct an analysis of individuals with DS who were hospitalized with COVID-19 in New | Retrospective, dual-center study of 7246 patients hospitalized with COVID-19, we analyzed all patients with DS | Hospitalized individuals with DS are on average ten years younger than patients without DS. Patients with DS have more severe disease than controls, particularly an |

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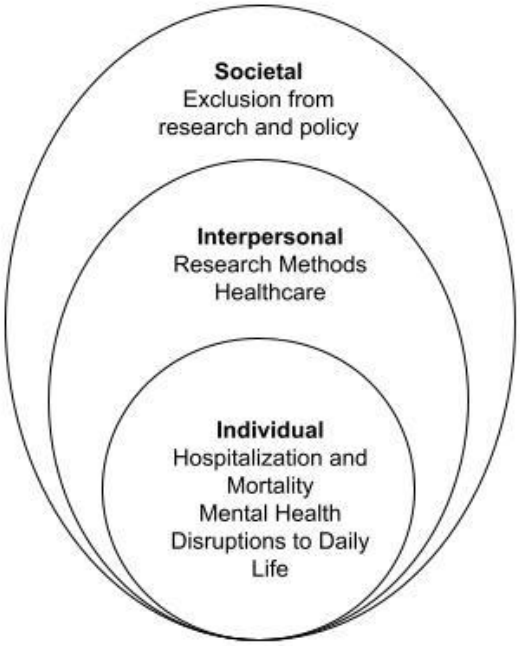
| 576-580. 10.1038/s41436-020-01004-w | York, New York, USA. | admitted in the Mount Sinai Health System and Columbia University Irving Medical Center. We assessed hospitalization rates, clinical characteristics, and outcomes. | increased incidence of sepsis and mechanical ventilation |
| Rosencrans, M., Arango, P., Sabat, C., Buck, A., Brown, C., Tenorio, M., & Witwer, A. (2021). The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities. Research in Developmental Disabilities, 114, 103985. 10.1016/j.ridd.2021.103985 | To explore mental health problems and services in individuals with IDD during the pandemic. We explored whether number of mental health problems differed by disability, age, gender, living situation, physical health, and access to services. | Online survey of adults with IDD and caregivers in US and Chile. US n = 404 (75% with helper); completed July 2020 | US sample reported difficulty accessing/changes in services. 9% increased health problems, 15% difficulty accessing healthcare, 29% feeling scared to go to the doctor. 41% reported more mental health problems since COVID began |
| Turk, M. A., Landes, S. D., Formica, M. K., & Goss, K. D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disability and health journal, 13(3), 100942. 10.1016/j.dhjo.2020.100942 | To compare COVID-19 trends among people with and without IDD, overall and stratified by age. | TriNetX COVID-19 database: electronic medical records from 42 health care organizations. Data from all patients with COVID-19 diagnosis through May 14 2020 ( n = 30282) | People with IDD had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Distinct age-related differences in COVID-19 trends were present among those with IDD, with a higher concentration of COVID-19 cases at younger ages. In addition, while the overall case-fatality rate was similar for those with IDD (5.1%) and without IDD (5.4%), these rates differed by age: ages ≤17 – IDD 1.6%, without IDD <0.01%; ages 18–74 – IDD 4.5%, without IDD 2.7%; ages ≥75– IDD 21.1%, without IDD, 20.7%. |

**Figure 1.** Applying the Social Ecological Model to Epistemic Injustice and the Impact of COVID-19



# Chapter 3

## Proxy-Responses in Research on COVID-19 Impacts for People with Intellectual and Developmental Disabilities

Like most disasters, the COVID-19 pandemic has not affected all groups equally, but disproportionately impacted people from already marginalized groups (Garnier et al., 2021; Gwynn, 2021; Weibgen, 2014). Literature suggests that people with intellectual and developmental disabilities (IDD) may be particularly vulnerable compared to people without disabilities. However, because people with IDD have been excluded from research before and during the COVID-19 pandemic and public health response, relatively little is known about their experiences.

The need to include people with IDD in research and the consequences of failing to do so predates the COVID-19 pandemic. Doody (2018) argues that academic researchers cannot fully understand concepts like health and wellness without integrating the voices of people with IDD. Additionally, excluding people with IDD from research perpetuates existing power imbalances that give people with IDD little control over their lives, including the opportunity to participate in research about them (Murray, 2018).

While the need to include people with IDD in research is well established, there are challenges to doing so. People with IDD are often viewed as a vulnerable population subject to increased protection and oversight from ethics boards (Doody, 2018; McDonald et al., 2016; Stack & McDonald, 2014). While these policies arose in response to a history of harmful and unethical research performed on people with disabilities, they have often led to people with IDD being fully excluded from research (Doody, 2018; McDonald et al., 2016; Stack & McDonald, 2014). Ethics committees and institutional review boards are often unfamiliar with intellectual and developmental disabilities and may believe that all people with IDD are unable to provide consent (Doody, 2018; Stack & McDonald, 2014). Additionally, McDonald and colleagues (2016) suggest that researchers may underestimate the interest people with IDD have in participating in research and so do not even consider the possibility of including them.

Beyond the ethical challenges of including people with IDD in research, there are practical difficulties to making research accessible (Stack & McDonald, 2014). Compared to more traditional academic research, conducting research with people with IDD costs more, takes more time, and requires more people, all of which can present a challenge for academic researchers (Walmsley et al., 2017). Creating accessible research materials is challenging, especially for people who do not communicate verbally (Scott and Havercamp, 2018; Stack and McDonald, 2014).

Because of these difficulties, research with people with IDD frequently allows for proxy responses to survey questions (Claes et al., 2012; Graves et al., 2016; Koch et al., 2015; Scott & Havercamp, 2018; Tourneir et al., 2020). However, literature suggests that proxy responses may not be valid substitutes for self-report, particularly for more subjective measures (Claes et al., 2012; Scott & Havercamp, 2018; Tourneir et al., 2020). For example, in their analysis of self- and proxy responses on measures of health, stress, and social support, Scott and Havercamp (2018) found that correlations between respondents was lower for subjective measures (ex. rating of overall health) compared with objective measures (ex. counts of physical activity). Similarly, in their study of the quantity and quality of family networks of people with IDD, Tourneir and colleagues (2020) found significant differences between self-reports and reports from staff-proxies.

In advocating for inclusive research methods, Hollomotz (2018) argued that for more subjective questions, proxy respondents may not be able to fully separate their own views, so that their answers may be more reflective of their own values and ideas. In support of this claim, Tournier and colleagues (2020) found that self- and proxy-perceptions of family networks differed more when the person with IDD had more externalizing behavior. The authors suggest that staff members' feelings towards the person with IDD may influence the ways that they answer questions on their behalf (Tournier et al., 2020).

## People with IDD and COVID-19

Despite the challenges of including people in IDD in research, finding ways to do so is vital, particularly in understanding an unprecedented event like the COVID-19 pandemic. The research that does exist suggests that people with intellectual and developmental disabilities (IDD) may have been at a heightened risk for poor outcomes from COVID-19, including high rates of hospitalization and death (Clarke et al., 2022; Gleason et al., 2021). In addition to the impacts of the COVID-19 virus itself, people with IDD faced major disruptions to their daily lives due to the public health response to slow the spread of the virus. Many people with IDD stopped working in the community (Carey et al., 2022; Fisher et al., 2022; Linehan et al., 2022), participated in fewer social activities and community events (Carey et al., 2022; Friedman, 2021), and to have changes in their services and supports (Linehan et al., 2022; Rosencrans et al., 2022) compared to before the COVID-19 pandemic. Several studies also found that people with IDD had increased stress, anxiety, and depression since the pandemic began (Carey et al., 2022; Fisher et al., 2022; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2021). Notably, most research on the experiences of people with IDD in the COVID-19 pandemic utilized proxy responses or secondary data analysis. While the COVID-19 pandemic resulted in additional challenges with conducting research, more work is needed to explore whether these methods accurately reflect the voices of people with IDD.

## Testimonial Injustice

Epistemic injustice, a theory proposed to understand and explain injustices related to knowledge, can be used to examine who is included in research and in knowledge creation (Fricker, 2007). Fricker (2007) suggests two main forms of epistemic injustice: testimonial and hermeneutical injustice. Both forms of epistemic injustice occur because of negative stereotypes, or associations with a personal attribute, and prejudices, or negative beliefs based on these assumptions (Fricker, 2007). Testimonial injustice occurs when a person is not seen as a credible witness because of these stereotypes and prejudices and are not given the opportunity to speak to their own experiences (Fricker, 2007). Hermeneutical injustice describes the phenomenon in which prejudices and stereotypes about a person or group of people excludes them from the collective understanding and the process of knowledge creation (Fricker, 2007). While both forms of epistemic injustice have important implications for research with people with IDD, this paper will primarily use the framework of testimonial injustice to understand what is known about the experiences of people with IDD in the COVID-19 pandemic.

In her original conceptualization of epistemic injustice, Fricker (2007) proposed that pursuing testimonial justice, where people are empowered to speak on their own experiences and to be believed, “serves equally both justice and truth” (pp. 121). Proponents of inclusive research with people with IDD echo this sentiment, arguing that finding ways to center the voices of people most affected by the research simultaneously improves the quality of the research findings and promotes inclusion and emancipation more broadly (Doody, 2018; Murray, 2018).

It is important to emphasize that testimonial injustice does not necessarily mean that negative stereotypes or prejudices about groups of people are consciously believed or endorsed (Fricker, 2007). However, the first step in promoting testimonial justice through equitable access to research is by critically examining the ways in which prejudices have become embedded in the social consciousness (Fricker, 2007). As such, the aim of this article is not to critique previous research methods or the use of proxy responses as a whole, but rather to employ a relatively novel statistical tool to explore the agreement between proxy- and self-responses.

## Network Analysis

Exploratory Graph Analysis (EGA) is an emerging tool in the field of network psychometrics that can be used to estimate the dimensional structure of instruments or constructs (Golino & Epskamp, 2017; Peralta et al., 2020). Golino and Epskamp (2017) suggested that EGA may be the preferred method of estimating dimensions compared to more widely used methods like exploratory factor analysis (EFA) or principle component analysis (PCA), especially when factors are highly correlated, the sample size is small, and each factor has a small number of indicators. EGA also uses a machine learning algorithm to estimate both the number and composition of dimensions (Kyriazos et al., 2021). Finally, EGA allows for multiple connections among variables, so that variables may be associated with more than one cluster (Golino & Epskamp, 2017).

EGA has been used in psychology research to model the relationships of symptoms of mental health conditions (Bos et al., 2018). Bos and colleagues (2018) suggest that focusing on the relationships of symptoms allows for a more nuanced understanding of mental health conditions than a more traditional measurement approach of using the sum-score of an individual's symptoms. Additionally, EGA allows researchers to identify highly influential symptoms that may be critical for understanding the etiology and treatment of a mental health condition (Bos et al., 2018; Robinaugh et al., 2016).

Outside of psychology, EGA has been used to understand a range of phenomena, including the impacts of COVID-19 (Kyriazos et al., 2021). EGA is a particularly useful tool for exploring people's experiences with the pandemic because of its ability to model complex connections between personal characteristics and global health trends (Kyriazos et al., 2021). Furthermore, given the paper's focus on examining how current COVID-19 research has captured the experiences of people with IDD, EGA allows analysis to be data-driven, without influence from prior assumptions (Kyriazos et al., 2021).

### Research Questions

Guided by the framework of testimonial justice, this paper aims to investigate methodological and ethical implications of  proxy responses in research with people with IDD with a particular focus on understanding the impacts of COVID-19. Specifically, this paper will address the following questions:

1). What are the differences in demographic, disability, and systemic factors between people who respond independently, via proxy, or with a mix of response types?

2). Does the dimensional network structure of COVID-19 impact differ based on whether a participant responds independently, via proxy, or with a mix of both response types?

## Methods

### Ethical Oversight

This study was reviewed and approved by the institutional review board at the author's affiliated university.

### Data

### National Core Indicators In-Person Survey

Data for this paper came from the 2020-2021 National Core Indicators In-Person Survey (NCI-IPS). The National Core Indicators project is a collaborative effort between participating states, the National Association of State Directors of Developmental Disability Services (NASDDDS), and the Human Services Research Institute (HSRI). The project measures outcomes for people with IDD who use state funded services in a variety of domains, including self-determination, relationships and community inclusion, health and wellness, and rights, choice, and decision making (NASDDDS & HSRI, n.d.). The project is designed to track these outcomes over time and between states, as well as to establish national benchmarks for service quality (NASDDDS & HSRI, n.d.). To meet these aims, participating states must achieve a sufficient random sample of people who use state-funded developmental disability services to allow for comparisons between states with at least a 95% confidence interval. For most states a sample of about 400 people meets this requirement, though some states choose to oversample for a variety of reasons.

Most years, the NCI-IPS consists of three sections. The background section is completed prior to the face-to-face interview, generally by a case manager. This section contains information about the participant’s demographics, diagnoses, and support needs. Section I may only be answered directly by the participant and contains subjective questions about their quality of life and satisfaction with services. Finally, Section II asks more objective questions about the participant’s rights, choice, and community participation which may be answered either by the participant or by someone who knows them well. Each item in this section is preceded by a question that asks who responded.

In the 2020-2021 and 2021-2022 data collection cycles the NCI-IPS included a fourth section about the impact of COVID-19. The COVID-19 Supplement could be answered by either the participant or a proxy. Like Section II, items in the supplement are preceded by a question that asks who responded. The variables of interest in this analysis came from the 2020-2021 COVID-19 supplement and are presented in Table 1. Demographic variables used to compare groups came from the background section of the 2020-2021 survey.

## Analyses

Analyses were conducted using R (R Core Team, 2017). First, the response variables in Section II were used to classify each case as “independent”, “proxy,” or “mixed” response type, where independent indicates that a person responded to every question themselves, proxy indicates that another person answered every question on behalf of the respondent, and mixed indicates a combination of these response types. Chi-squared tests were then used to examine univariate differences in response frequencies and patterns between response types. Exploratory graph analysis (EGA) was then used to estimate a multivariate graphical model of the selected variables to visually represent the impacts of COVID-19 for each response category (Bos et al., 2018; Golino & Epskamp, 2017).

### Network Estimation.

The R package EGAnet (Golino & Christensen, 2020) was used to estimate network models for the full sample and for each response category. EGA applies a Gaussian graphical model, estimated using the graphical least absolute shrinkage and selection operator (glasso), a regularization technique that avoids overfitting by setting small partial correlation coefficients to zero (Golino & Epskamp, 2017). Next, the walktrap algorithm identifies communities, or clusters of closely connected variables, based on “random walks” or steps between variables in the network (Golino & Epskamp, 2017). Golino and Epskamp (2017) argue that these communities can be interpreted as similar to latent constructs in structural equation modeling (SEM). EGA then produces a visual representation of the network structure, in which each node represents a variable. Nodes are connected by edges, which represent partial Pearson's correlations between two variables, controlling for all other variables in the network.

In addition to a visual comparison of network structures, networks for each of the four categories were also compared using the following analyses.

### Centrality Estimation

The qgraph package (Epskamp et al., 2012) was used to measure the importance of each node to the network on four centrality indices: strength, closeness, betweenness, and expected influence (EI). Generally, centrality is a measure of the amount of influence that each node exerts on the other variables in the network. Strength is the sum of the absolute value of a node's connections (edges) with other nodes in a network (Robinaugh et al., 2016). EI is also a sum of a node's connections but includes negative edge weights rather than the absolute value. Closeness measures the average shortest path between a given node and other nodes in the network and betweenness measures the number of times a node lies on the shortest path between two other nodes (Robinaugh et al., 2016). Based on the recommendations of previous researchers (Peralta et al., 2020; Robinaugh et al., 2016), this paper used EI as the main centrality measure because of its ability to account for the influence of negative edges in a network.

### Network Comparison

The Network Comparison Test (NCT) package was used to compare networks (van Borkulo et al., 2017). The NCT is a permutation-based test which repeatedly measures network connectivity on randomly re-grouped participants. The NCT assesses differences in global strength and network structure. Global strength is a measure of the overall connectivity of a network, equal to the absolute weighted sum of all the network's edges. Network structure is a measure of the distribution of edge weights. Statistically significant differences in these tests suggest that differences between networks are meaningful, as response patterns and in connections between variables beyond what would be expected due to chance alone.

## Results

### Response Categories

Sample characteristics are presented for the full sample and by response category in Table 2. Data came from respondents in 26 states, for a total sample of 19,991. Of this, 235 cases were missing a designation for respondent for at least one variable, leaving a sample of 19,756 for the remaining analysis. Respondents were most likely to answer via proxy (40.87%), followed by independently (33.25%) and with a mix of respondents (25.38%). Respondents were mostly male (59.0%) and White (60.6%). Smaller percentages of respondents identified as Black (14.3%) and Latinx (16.8%). Eight participants identified as a gender identity other than male or female. Most respondents had a mild (34.00%) or moderate (24.71%) intellectual disability, communicated verbally (73.12%), and were their own legal guardian (58.26%).

### Bivariate Analysis

Significant differences between the response categories in demographic, disability, and system characteristics are presented in Table 2. People who were younger ($F(1) = 65.94$, $p < .001$), Black ($X^2(2) = 16.63$, $p < .001$), and who had a mild intellectual disability ($X^2(8) = 4293.09$, $p < .001$) were more likely to answer the survey independently. In contrast, people who were older ($F(1) = 65.94$, $p < .001$), Latino ($X^2(2) = 34.84$, $p < .001$), and who had a severe or profound intellectual disability ($X^2(8) = 4293.09$, $p < .001$) were more likely to participate via proxy response. Unsurprisingly, people who answered via proxy were more likely to communicate nonverbally ($X^2(2) = 4169.49$, $p < .001$), and to have a legal guardian ($X^2(2) = 887.66$, $p < .001$).

Differences in the variables related to COVID-19 are highlighted in Table 3. With the exception of stopping going to school and having time when help was not available, all of the variables related to COVID-19 differed significantly between participants who answered independently, via proxy, or with a mix of response types. Important differences were seen in participants reporting stopping paid work in the community: 20.34% of people who responded independently reported this change, compared to 4.51% of people who responded via proxy, and 16.83% of people who answered using a mix of response types ($X^2(2) = 805.82$, $p < .001$). People who answered independently and with a mix of response types were also more likely than people who answered via proxy that they felt more worried, scared, or anxious since the start of the COVID-19 pandemic ($X^2(2) = 484.44$, $p < .001$). Proxy respondents were significantly more likely to report needing reminders to wash hands ($X^2(2) = 3364.81$, $p < .001$), wear a mask ($X^2(2) = 3033.65$, $p < .001$), and social distance ($X^2(2) = 2988.56$) compared to people who answered independently, with those who used a mix of response types falling in between.

## Network Structure

Models for the full sample, self-response, proxy-response, and mixed-response categories are presented in Figures 1, 2, 3, and 4 respectively and in Table 4.

Six communities emerged for the full sample, compared with five for the proxy- and mixed-response samples and seven communities for the self-report sample. While the specific clusters varied, some similarities were seen across models. Three variables related to changes in one’s housing, changes in daily supports, and needing additional help clustered together in all four networks. Feeling increased anxiety clustered with these variables for participants who answered the survey independently. The three variables related to health reminders (reminders to mask, wash hands, and social distance) also clustered together in all four networks. Variables related to changes in social connections and community participation clustered together in all groups except for the full sample, though the exact combination of variables differed somewhat between groups. Similarly, the importance of technology as a means to facilitate connection during COVID-19 emerged as a cluster for all four groups, though the exact clusters varied.

Other variables behaved differently across groups. For example, changes to one's day program and job clustered together for the full sample and mixed-response group, but formed separate clusters in the group that answered the survey independently or via proxy.

## Centrality Estimation

EI centrality estimates differed between variables but were fairly consistent across groups. Figure 5 presents the expected influence of each node for each of the four networks. Tables 5 through 8 present the expected influence for each network separately, with nodes ordered in decreasing EI. A similar pattern of EI was observed across networks. While the order differed, variables related to health reminders (washing hands, wearing a mask, and social distancing) and to participating in the community less were the most influential in networks for all four response types. Notably, stopping one's job was only highly influential in the proxy-response category.

## Network Comparison

The mixed-response group differed from both the self-response and proxy-response groups in network strength ($p < .05$). All three groups varied significantly in network structure ($p < .05$), though the difference between the proxy- and mixed-response groups had borderline significance (p = .055). These findings suggest that group membership significantly impacted the network of variables related to COVID-19.

# Discussion

## Impact of COVID-19

Despite differences in the network structures based on the four response categories, some important themes emerged that support previous research on the impact of the COVID-19 pandemic on people with IDD. Consistent with prior literature, this study suggests that people with IDD experienced changes in their living arrangement and/or in-home services, which negatively impacted the care they received (Hartley et al., 2022; Linehan, 2022). For people who answered via proxy and with a mix of responses, both changes in where they lived and in the supports that they received were positively associated with experiencing times when needed help was not available. This pattern was slightly different for people who answered the COVID-19 supplement independently. A change in in-home supports was positively associated with having experienced times when help was unavailable, but moving was negatively associated with lacking needed help.

The networks for all response categories had clusters of variables related to social relationships and community participation, which also supports previous research on the impact of COVID-19 (Carey et al., 2022; Fisher et al., 2022). Seeing friends and family less often or not in person was closely related to going into the community less for people who answered independently, via proxy, or with a mix of response types, though the associations with other variables differed based on who answered the survey. For people who answered the survey independently, these two variables did not cluster with any other items in the COVID-19 supplement, while for other response types seeing friends and family and going into the community less were parts of larger clusters of variables.

The differences observed through visually examining the network structures for people who responded to the COVID-19 Supplement independently, via proxy, or with a mix of responses were also reflected in the statistical comparison networks. Results from the Network Comparison Test (NCT) support the claim that network structures differ significantly based on response-type beyond what would be expected from chance alone. This finding is particularly important given the large variation in personal characteristics between response categories. People who answered the survey via proxy- or mixed-response were more likely than people who answered independently to have more significant levels of intellectual disability, to communicate using methods other than speech, and to have a legal guardian. Clearly, understanding the factors that make people less likely to answer a survey independently has vital implications for making research accessible for people with IDD. However, these characteristics alone cannot explain the differences in networks between people who answered independently, via proxy, or with a mix of responses.

## Implications for Practice

Beyond differences in the overall pattern of responses and associations, centrality estimates, specifically EI, behave differently across networks. As described previously, literature suggests that identifying highly influential nodes in a network is critical for understanding a phenomenon and, when necessary, intervening to improve outcomes (Bos et al., 2018). While some differences were observed across response categories, general patterns emerged in all networks that can offer insight into the impacts of the COVID-19 pandemic and associated public health response. For three of the four response categories (self-response, mixed response, and the full sample), the four most influential nodes were needing reminders to wash one’s hands, social distance, and wear a mask, and going into the community less or not at all. For people who answered via proxy the most influential nodes were reminders to wash one’s hands and mask, going out into the community less, and stopping a paid job. These findings suggest that participating in the community for employment or leisure were particularly important for people with IDD and that they may have needed additional support to do so safely in the context of COVID-19.

The end of paid community employment was only highly influential in the proxy-response group. While more research is needed to understand this difference, it is possible that proxy respondents overestimated the importance of paid work and that other ways of interacting with the community may be equally or more valuable to people with IDD. For example, Lysaght and colleagues (2016) found that social connection was a primary motivator of employment for people with IDD. Feeling included may matter more than the work itself, as evidenced by the importance of community participation in all response categories (Lysaght et al., 2016).

Using technology to connect with important people, including friends and family, case managers, and medical providers, emerged as a pattern in all four networks, though the exact relationships and variables differed. Associations were generally small, but positive: people who had a smartphone, tablet, or computer and who had reliable internet were more likely to talk to family and friends and their case manager as often as they wanted and were more likely to have used video conferencing to talk to a healthcare provider. For the proxy- and self-response networks, feeling more anxious, sad, scared or worried clustered with variables related to technology; people who had reliable internet were less likely to report these feelings.

The importance of connecting virtually in this study echoes previous suggestions that the quality of social interactions matters more than the number of activities (Spassiani et al., 2022). In fact, moving activities online may have made community spaces more accessible for some people with disabilities (Shew, 2020). In this study, the majority of people reported that their internet worked well (82.27%) and that they had a smartphone, tablet, or other device that they could use to communicate with people who did not live with them. Families, support workers, and case managers should consider, however, that people with IDD may need support and instruction to learn how to use these devices (Spassiani et al., 2022).

## Implications for Research

While similar clusters emerged in each of the four networks, differences in network strength and structure suggest that there are differences between self-, proxy-, and mixed-responses to the NCI-IPS COVID-19 supplement. This finding supports previous researchers who reported limitations to the validity of proxy responses in research with people with IDD (Claes et al., 2012; Graves, 2012; Scott & Havercamp, 2018).

While there are ethical and practical considerations for including people with IDD in research, promoting equity and testimonial justice requires researchers to confront these challenges (Doody, 2018; McDonald et al., 2016). Doing so may improve the validity of research findings by ensuring that the voices and experiences of people with IDD are centered, which may in turn allow for more effective interventions (McDonald et al., 2016). At a higher level of impact, including people with IDD in research can challenge negative assumptions about people with IDD and promote inclusion in other life domains as well (McDonald et al., 2016).

Findings from this study support those from Claes and colleagues (2012), who argue that proxy responses provide comparable data to self-reports, but that the two sources of data are not interchangeable. While similar clusters of impact emerged for all four response categories in this study, both visual and statistical examination reveal differences in network structure between people who responded independently, via proxy, or with a mix of response types. To account for these differences, Claes and colleagues (2012) recommend that proxy and self-report data should be analyzed and reported separately.

Prior literature is also clear that proxy responses should be limited to objective, observable questions (Claes et al., 2012; Scott & Havercamp, 2018). Many of the variables on the NCI-IPS meet this recommendation–they are objective questions about whether or not the participant experienced certain changes during the COVID-19 pandemic. Other questions, however, are far more subjective (reference table of variables). For example, participants were asked if they felt more worried, anxious, or scared since the start of the pandemic and if they were able to talk with friends and family members who didn't live with them "as much as you wanted".

Supporting the recommendations of previous researchers, the impact of some of these more subjective variables seems to differ across networks. Having instances where needed help was not available was associated with a change in residence or in-home supports for the proxy-response sample, but with the community participation cluster in the self-response sample. Similarly, talking with friends and family clustered with community participation in the proxy-response and full sample, but with variables related to technology in the mixed-response sample and in a small cluster of only participating in the community and seeing family and friends in the self-response sample. However, feeling more worried consistently clustered with community participation variables across response categories.

## Limitations and Directions for Future Research

This study has several important limitations that offer avenues for future exploration into the use of proxy responses and inclusive research for people with IDD. Firstly, it must be noted that the term “IDD” refers to a broad range of conditions and describes a heterogeneous population of people with diverse experiences, diagnoses, and support needs (Schalock et al., 2019). In this study,  people with more significant levels of intellectual disability, people who communicated in ways other than speech, and people with a legal guardian were more likely to respond via proxy or with a mix of response types. While the network comparison test suggests that these characteristics do not fully account for the differences in network structure, previous literature has found that people with more significant support needs are least likely to participate in research (de Haas et al., 2022). Additional work is needed to develop more accessible research strategies, including the strategic use of proxy responses when necessary.

Additional research should also consider the impact of different types of proxy respondents. For the purposes of this paper, all proxy responses were grouped into a single category. It is possible, however, that differences exist based on the relationship the respondent had with the person with IDD. For example, while Claes and colleagues (2012) found that no proxy-response perfectly matched self-reported data, responses from family members aligned more closely with self-responses than responses from staff. The NCI-IPS and COVID-19 supplement identifies respondents as friend/family, staff, or other. Future studies may wish to further specify the “proxy” and “mixed” categories to explore these differences.

There are also limitations with the data used in this analysis. Firstly, rates of missingness were high for the COVID-19 supplement. Any variable that had higher than 20% missing was excluded from the analysis, and rates of missing for the included variables ranged from .24% to 7.80%. This missingness may have been due in part to the nature of the NCI-IPS survey. The

COVID-19 supplement was the last section of a long interview and participants may have declined to answer. The timing of the COVID-19 supplement may also have influenced the rate of proxy respondents if participants were more likely to use a proxy at the end of the survey.

Notably, one area in which analyses were limited due to high missingness was the role of technology during the COVID-19 pandemic. The COVID-19 supplement included a series of questions asking if respondents had used technology to participate in specific events, including social groups. All of these items had more than 20% missingness, and so were excluded. Future research may wish to more closely examine how technology can facilitate connection and inclusion.

Finally, this survey data is cross-sectional. While the COVID-19 supplement asked respondents to consider how their lives had changed during “COVID times”, since the start of the pandemic, these data still only represent a single point in time during an ongoing global emergency.

## Conclusion

This paper supports prior research that suggests that people with IDD faced significant disruptions to their everyday lives due to the COVID-19 pandemic. Additionally, using the framework of testimonial injustice to examine the ways in which the voices of people with IDD were included in the research about COVID-19, this paper supports literature that argues that proxy-responses may not be exact replacements for self-response in survey research. While challenging, finding ways to include people with IDD in research can improve the validity of findings and outcomes while simultaneously promoting inclusion and challenging injustice.

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# Tables and Figures

Table 1. COVID-19 Variables

| Abbreviation | COVID-19 Supplement Question |
|---|---|
| Move | Did you/this person move, or change where you live? |
| Supports | (If you did not move) were there changes in your/this person's in-home supports? |
| Stop_day | Did you/this person stop going in-person to day program, workshop, or other unpaid day/community activity? |
| Hours_day | Did you/this person go fewer hours to day program, workshop, or other unpaid day/community activity? |
| Stop_job | Did you/this person stop working at a paid job in the community? |
| Hours_job | Did you/this person work fewer hours at a paid job in the community? |
| See_famfrnd | Did you/this person see friends and family who don't live with you less often or stop seeing them in person? |
| Community | Did you/this person go into the community (stores, restaurants, theaters, etc.) less often or stop going? |
| Stop_school | Did you/this person stop going to school in-person? |
| Worried | Since COVID time started, have you been more worried, scared, anxious or sad than before? |
| Tech_device | Is there a computer, tablet, or smartphone that you can use in your home? |
| Internet | How does your internet work at home? |
| Talk_FAMFRND | Since COVID time started, have you talked to your friends and family as much as you want? |
| Talk_cm | Since COVID time started, have you talked to your case manager/service coordinator enough? |
| Video_cm | Have you ever talked to your case manager/service coordinator using video conference or telehealth like Skype, Zoom or FaceTime? |
| Video_med | Have you ever talked to any health professionals using video conference/telehealth like Skype, Zoom, or FaceTime? |
| Wash_hands | Do you need more help or reminders to wash your hands regularly during the day? |
| Wear_mask | Do you need more help or reminders to wear a mask when you go outside or to places where other people are? |
| Have_mask | Is there always a clean mask for you to use when you want or need one? |
| Social_dist | Do you need more help or reminders to stay far enough away from people when you're out in the community so germs don't spread? |
| Staff_ppe | Since COVID time started, have your staff used personal protective equipment (PPE)? |
| Need_help | Since COVID time started, have there been times when you didn't have the help you needed? |

Table 2. Personal Characteristics by Response Category

| | Self (N = 6000) | Proxy (N = 7267) | Mix (N = 4513) | Total (N = 17780) | df | F or X2 |
|---|---|---|---|---|---|---|
| Age (54) | 39.18 (14.12) | 41.89 (16.34) | 42.17 (15.87) | 41.05 (15.58) | 1 | 65.94*** |
| Gender (65) | | | | | 2 | 10.27** |
| Female | 2529 (42.29%) | 2873 (39.70%) | 1880 (41.80%) | 7282 (41.11%) | | |
| Male | 3451 (57.71%) | 4364 (60.30%) | 2618 (58.20%) | 10433 (58.89%) | | |
| Race | | | | | | |
| Black | 886 (15.22%) | 959 (13.78%) | 540 (12.41%) | 2385 (13.92%) | 2 | 16.63*** |
| Latino | 1019 (17.51%) | 1382 (19.86%) | 677 (15.56%) | 3078 (17.97%) | 2 | 34.84*** |
| White | 3496 (60.07%) | 3870 (55.61%) | 2757 (63.36%) | 10123 (59.10%) | 2 | 70.03*** |
| Other | 127 (2.16%) | 150 (2.13%) | 84 (1.91%) | 361 (2.08%) | 2 | .85 |
| Type of home (236) | | | | | 14 | 1880.99*** |
| ICF/Nursing home | 125 (2.10%) | 665 (9.29%) | 165 (3.72%) | 955 (5.44%) | | |
| Group 2-3 | 482 (8.11%) | 552 (7.71%) | 285 (6.42%) | 1319 (7.52%) | | |
| Group 4-6 | 817 (13.75%) | 1703 (23.78%) | 907 (20.43%) | 3427 (19.53%) | | |
| Group 7-15 | 145 (2.44%) | 179 (2.50%) | 128 (2.88%) | 452 (2.58%) | | |
| Independent | 1701 (28.63%) | 338 (4.72%) | 533 (12.00%) | 2572 (14.66%) | | |
| Family | 2343 (39.43%) | 3272 (45.69%) | 2074 (46.71%) | 7689 (43.83%) | | |
| Host | 300 (5.05%) | 426 (5.95%) | 326 (7.34%) | 1052 (6.00%) | | |
| Other | 29 (0.49%) | 27 (0.38%) | 22 (0.50%) | 78 (0.44%) | | |
| Level of ID (3079) | | | | | 8 | 4293.09 *** |
| Mild | 3108 (70.81%) | 1186 (18.35%) | 1826 (47.43%) | 6120 (41.63%) | | |
| Moderate | 926 (21.10%) | 1970 (30.49%) | 1356 (35.22%) | 4252 (28.92%) | | |
| Severe | 73 (1.66%) | 1614 (24.98%) | 278 (7.22%) | 1965 (13.37%) | | |
| Profound | 12 (0.27%) | 1096 (16.96%) | 81 (2.10%) | 1189 (8.09%) | | |
| Autism (366) | | | | | 2 | 161.16*** |
| No | 4722 (79.95%) | 5157 (72.65%) | 3605 (81.75%) | 13484 (77.43%) | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| Yes | 1184 (20.05%) | 1941 (27.35%) | 805 (18.25%) | 3930 (22.57%) | | |
| Communication (112) | | | | | 2 | 4169.49 *** |
| Speaks | 5607 (93.83%) | 3432 (47.65%) | 3924 (87.39%) | 12963 (73.37%) | | |
| Other | 369 (6.17%) | 3770 (52.35%) | 566 (12.61%) | 4705 (26.63%) | | |
| Mobility (314) | | | | | 2 | 642.90*** |
| Independent | 4983 (84.60%) | 4722 (66.12%) | 3519 (79.36%) | 13224 (75.71%) | | |
| Needs assistance | 907 (15.40%) | 2420 (33.88%) | 915 (20.64%) | 4242 (24.29%) | | |
| Legal guardian (255) | | | | | 2 | 887.66*** |
| No | 4529 (76.37%) | 3670 (51.24%) | 2606 (58.80%) | 10805 (61.65%) | | |
| Yes | 1401 (23.63%) | 3493 (48.76%) | 1826 (41.20%) | 6720 (38.35%) | | |

* $p < .05$ ** $p < .005$ ***$p < .001$

Table 3. COVID-19 Impact by Response Category

| | Self (N = 6000) | Proxy (N = 7267) | Mix (N = 4513) | Total (N = 17780) | df | X2 |
|---|---|---|---|---|---|---|
| MOVE (42) | 401 (6.70%) | 299 (4.13%) | 254 (5.64%) | 954 (5.38%) | 2 | 43.34*** |
| SUPPORTS (42) | 585 (9.77%) | 998 (13.78%) | 600 (13.32%) | 2183 (12.31%) | 2 | 54.36*** |
| STOP_DAY (42) | 2505 (41.83%) | 4583 (63.26%) | 2755 (61.15%) | 9843 (55.49%) | 2 | 687.65*** |
| HOURS_DAY (42) | 979 (16.35%) | 1410 (19.46%) | 966 (21.44%) | 3355 (18.91%) | 2 | 45.88*** |
| STOP_JOB (42) | 1218 (20.34%) | 327 (4.51%) | 758 (16.83%) | 2303 (12.98%) | 2 | 805.82*** |
| HOURS_JOB (42) | 507 (8.47%) | 108 (1.49%) | 238 (5.28%) | 853 (4.81%) | 2 | 351.52*** |
| SEE_FAMFRND (42) | 3947 (65.92%) | 4586 (63.30%) | 3187 (70.74%) | 11720 (66.07%) | 2 | 68.78*** |
| COMMUNITY (42) | 4894 (81.73%) | 6277 (86.64%) | 3877 (86.06%) | 15048 (84.83%) | 2 | 68.45*** |
| STOP_SCHOOL (42) | 561 (9.37%) | 623 (8.60%) | 371 (8.24%) | 1555 (8.77%) | 2 | 4.56 |
| WORRIED (698) | 2681 (45.88%) | 1952 (28.27%) | 1881 (43.41%) | 6514 (38.13%) | 2 | 484.44*** |
| TECH_DEVICE (226) | 5423 (91.20%) | 6078 (85.04%) | 3946 (88.46%) | 15447 (88%) | 2 | 117.85*** |
| INTERNET (1385) | 4320 (79.21%) | 5747 (84.70%) | 3421 (82.31%) | 13488 (82.27%) | 2 | 62.56*** |
| TALK_FAMFRND (1285) | 4195 (72.13) | 5747 (84.70%) | 3421 (82.31%) | 13488 (82.27%) | | 246.48*** |
| TALK_CM (773) | 4310 (74.93%) | 5990 (86.19%) | 3393 (78.82%) | 13693 (80.51%) | 2 | 264.78*** |
| VIDEO_CM (506) | 2955 (50.55%) | 4125 (58.62%) | 2539 (57.82%) | 9619 (55.68%) | 2 | 95.21*** |
| VIDEO_MED (400) | 2550 (43.40%) | 3894 (55.02%) | 2176 (49.15%) | 8620 (49.60%) | 2 | 174.07*** |
| WASH_HANDS (257) | 1167 (19.73%) | 5046 (70.58%) | 2035 (45.64%) | 8248 (47.07%) | 2 | 3364.81*** |
| WEAR_MASK (319) | 1209 (20.41%) | 4853 (68.43%) | 1858 (41.80%) | 7920 (45.36%) | 2 | 3033.65*** |
| SOCIAL_DIST (349) | 1278 (21.63%) | 4940 (69.75%) | 2153 (48.49%) | 8371 (48.02%) | 2 | 2988.56*** |
| HAVE_MASK (272) | 5748 (97.14%) | 7053 (98.86%) | 4383 (98.34%) | 17184 (98.15%) | 2 | 53.92*** |
| NEED_HELP (465) | 430 (7.42%) | 480 (6.70%) | 338 (7.75%) | 1248 (7.21%) | 2 | 5.05 |

* p < .05 ** p < .005 ***p < .001

**Figure 1.** Proxy-Response Network

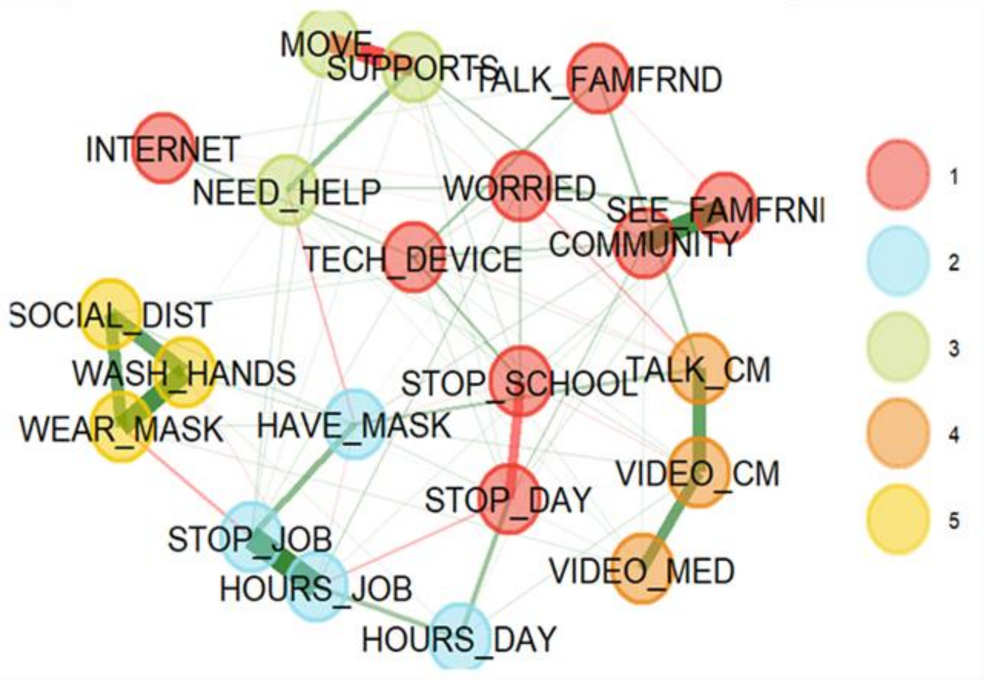

**Figure 2.** Self-Response Network

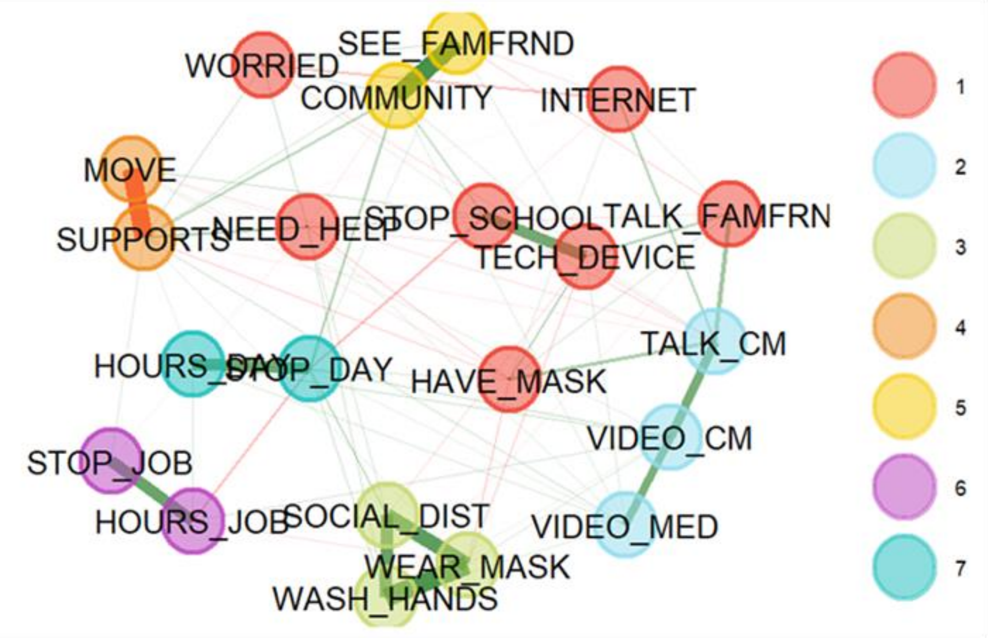

**Figure 3.** Mixed-Response

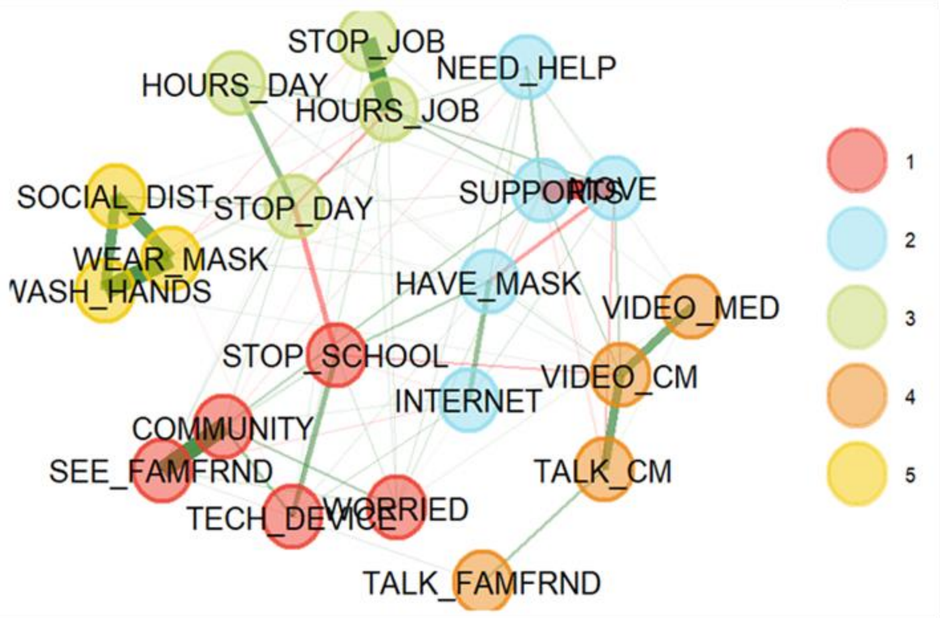

**Figure 4.** Full Sample

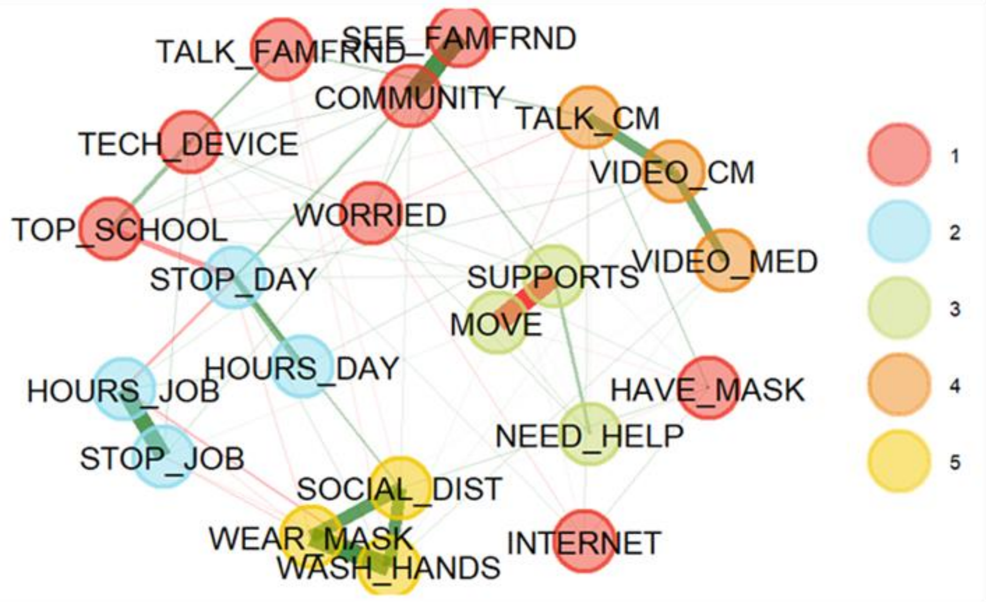

**Figure 5.** Expected Influence

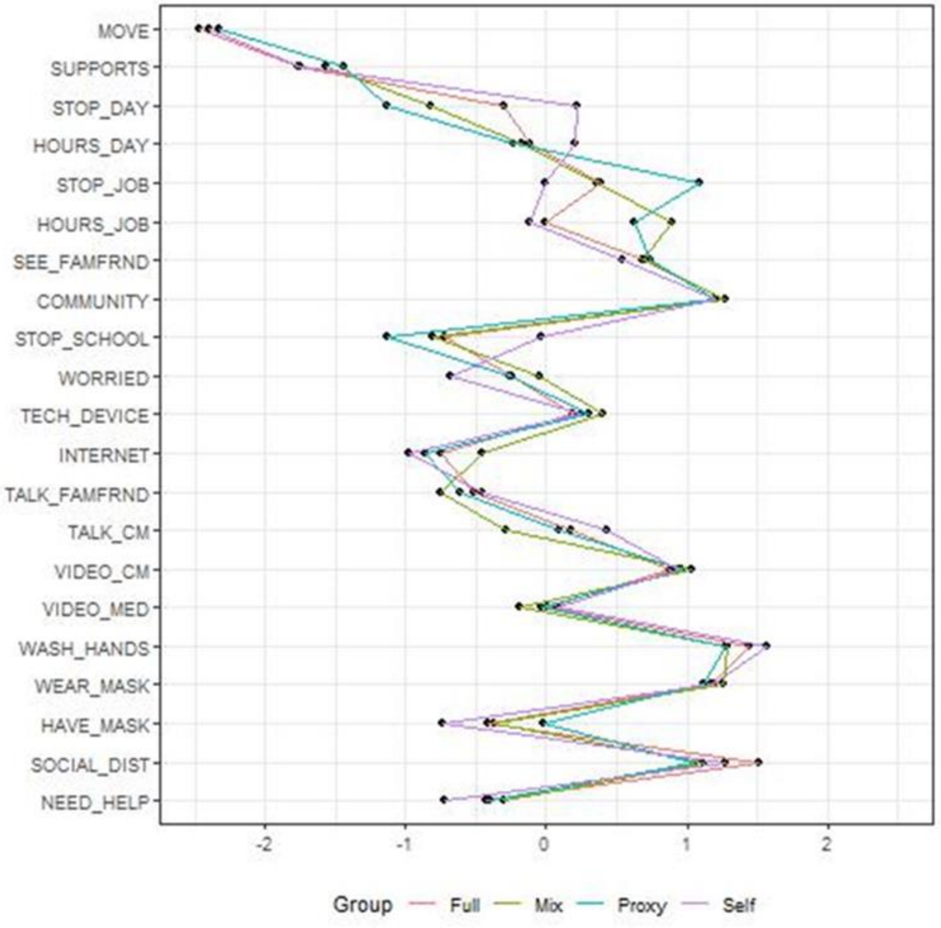

**Table 5.** Proxy-Response Expected Influence

| Variable | EI |
|---|---|
| WASH_HANDS | .892 |
| COMMUNITY | .864 |
| WEAR_MASK | .834 |
| STOP_JOB | .823 |
| SOCIAL_DIST | .806 |
| VIDEO_CM | .773 |
| SEE_FAMFRND | .690 |
| HOURS_JOB | .649 |
| TECH_DEVICE | .530 |
| TALK_CM | .451 |
| HAVE_MASK | .409 |
| VIDEO_MED | .406 |
| HOURS_DAY | .330 |
| WORRIED | .322 |
| NEED_HELP | .268 |
| TALK_FAMFRND | .193 |
| INTERNET | .096 |
| STOP_DAY | .000 |
| STOP_SCHOOL | -.002 |
| SUPPORTS | -.116 |
| MOVE | -.443 |

**Table 6.** Mixed Response Expected Influence

| Variable | EI |
|---|---|
| WASH_HANDS | .801 |
| COMMUNITY | .792 |
| WEAR_MASK | .788 |
| SOCIAL_DIST | .741 |
| VIDEO_CM | .715 |
| HOURS_JOB | .665 |
| SEE_FAMFRND | .596 |
| TECH_DEVICE | .500 |
| STOP_JOB | .486 |
| WORRIED | .351. |
| HOURS_DAY | .306 |
| VIDEO_MED | .301 |
| TALK_CM | .271 |
| NEED_HELP | .263 |
| HAVE_MASK | .240 |
| INTERNET | .212 |
| TALK_FAMFRND | .112 |
| STOP_SCHOOL | .095 |
| STOP_DAY | .089 |
| SUPPORTS | -.163 |

**Table 7.** Self-Response Expected Influence Table

| Variable | EI |
|---|---|
| WASH_HANDS | .900 |
| SOCIAL_DIST | .798 |
| COMMUNITY | .770 |
| WEAR_MASK | .766 |
| VIDEO_CM | .678 |
| SEE_FAMFRND | .542 |
| TALK_CM | .502 |
| TECH_DEVICE | .440 |
| STOP_DAY | .429 |
| HOURS_DAY | .423 |
| VIDEO_MED | .380 |
| STOP_JOB | .350 |
| STOP_SCHOOL | .342 |
| HOURS_JOB | .309 |
| TALK_FAMFRND | .193 |
| WORRIED | .116 |
| NEED_HELP | .100 |
| HAVE_MASK | .096 |
| INTERNET | .012 |
| SUPPORTS | -.260 |
| MOVED | -.485 |

**Table 8.** Full Sample EI

| Variable | EI |
|---|---|
| SOCIAL_DIST | .881 |
| WASH_HANDS | .857 |
| COMMUNITY | .796 |
| WEAR_MASK | .758 |
| VIDEO_CM | .652 |
| SEE_FAMFRND | .583 |
| STOP_JOB | .473 |
| TECH_DEVICE | .400 |
| TALK_CM | .396 |
| VIDEO_MED | .333 |
| HOURS_JOB | .327 |
| HOURS_DAY | .284 |
| WORRIED | .241 |
| STOP_DAY | .218 |
| HAVE_MASKS | .181 |
| NEED_HELP | .172 |
| TALK_FAMFRND | .143 |
| STOP_SCHOOL | .063 |
| INTERNET | .053 |
| SUPPORTS | -.315 |
| MOVE | -.572 |

# Chapter 4

## The Impact of State COVID-19 Responses on People with Intellectual and Developmental Disabilities

In the United States, the COVID-19 pandemic and resulting public health response has exposed longstanding inadequacies in the healthcare and emergency response systems (Gusmano et al., 2020). Like other disasters, the impact of the pandemic was not felt equally, but rather disproportionately disadvantaged people from historically marginalized backgrounds (Gusmano et al., 2020; Weibgen, 2014). Weibgen (2014) goes so far as to argue that nearly all disasters are, to some degree, socially constructed, as the disaster response relies on existing, biased, understandings of the world.

In the United States, the official response to the COVID-19 pandemic varied widely between states (Bergquist et al., 2020; Gusmano et al., 2020; Holtz et al., 2020; Xu & Basu, 2020). Gusmano and colleagues (2020) note that some variation in responses is necessary to account for state-level differences in population, infrastructure, and the spread of illness. However, the lack of a coordinated national response limited the effectiveness of local interventions and contributed to the politicization of public health decisions (Gusmano et al., 2020; Holtz et al., 2020; Xu & Basu, 2020). For example, in their analysis of states' initial responses to the COVID-19 pandemic, Gusmano and colleagues (2020) reported that the only states that did not issue stay-at-home orders were led by Republican governors. Furthermore, Holtz and colleagues (2020) found that county-level stay-at-home mandates were most effective at decreasing mobility when surrounding counties issued similar guidelines and least effective when surrounding localities did not have policies in place. These findings suggest that some level of federal oversight and coordination is necessary to ensure that public health responses account for interdependence and connections among people and regions (Gusmano et al., 2020; Holtz et al., 2020).

The US response to the COVID-19 pandemic was also limited by inadequate testing and reporting, in part due to unclear federal policies (Bergquist et al., 2020; Xu & Basu, 2020). Disease surveillance and control depends on large-scale testing, with established containment measures for high case rates and exit measures when cases drop (Bergquist et al., 2020; Xu & Basu, 2020). As with stay-at-home policies, in the United States, decisions about testing and reporting strategies were left to individual states, without federal coordination or adequate funding (Berquist et al., 2020; Xu & Basu, 2020).

Challenges with coordination and data were exacerbated for people with disabilities. Testing and surveillance rarely included usable disability identifiers to track case rates and outcomes as compared with people without disabilities (Boyle et al., 2020). For example, guidance on reporting cases among residents and staff in nursing homes and other long term care facilities was not issued until April of 2020 (Berquist et al., 2020). Additionally, COVID-19 testing in the community did not include disability identifiers that could be used to monitor outcomes for people with specific conditions (Berquist et al., 2020). Later, the lack of disability identifiers in testing data limited the ability to link other system-level data, including mortality data, to understand the impact of COVID-19 on people with disabilities (Berquist et al., 2020).

Beyond the limitations from poor quality data, pervasive ableism in the healthcare system further impacted the degree to which the public health response to COVID-19 protected people with disabilities. Despite high rates of people with IDD living in group homes and evidence that these settings placed people at increased risk from COVID-19 (Shapiro, 2020), official guidance for these residences was not issued until May 2020 (Landes et al., 2020). Other guidance, often based in a medical model that views disability as a deficit, discriminated against people with disabilities in allocating life-saving resources in a crisis situation (Center for Public Representation [CPR], 2020a).

### People with IDD and COVID-19

Compared to the general population, people with IDD may have been more likely to be hospitalized if they contracted COVID-19 (Clarke et al., 2022; Gleason et al., 2021). Furthermore, people with IDD may have been more likely to die from COVID-19 than people without disabilities (Clarke et al., 2022; Fair Health, 2020; Gleason et al., 2021). These differences may be partly related to how people with IDD live in the community. Landes and colleagues (2020) found that case fatality and mortality rates for people with IDD living in New York state-run residential settings were approximately twice the rates of the general population of the state. Understanding the factors underlying these risks is imperative for developing an equitable public health response.

Evidence is mixed on whether people with IDD contracted COVID-19 at a higher rate than the general population. A cross-sectional data analysis of 64 million patients from 547 health care organizations found that patients with IDD had more than three-times the rate of COVID-19 diagnosis compared to people without IDD (3.1% vs. 0.9%; Gleason et al., 2021). In contrast, Spreat and colleagues (n.d.) reported that people with and without IDD had a similar incidence of COVID-19 diagnosis, while an analysis of people with IDD receiving state-funded services in California found that incidence of COVID-19 per 100,000 was 60% lower than the incident proportion of the general population (Landes et al., 2021b).

The type of services people receive may have impacted their susceptibility to contracting COVID-19. Landes and colleagues (2020) found that the incidence proportion of COVID-19 among people with IDD who lived in state-funded group homes in New York was four times higher than that of the general population (7,841 per 100,000 vs. 1,910 per 100,000). These differences were particularly noteworthy in the early months of the pandemic (Landes et al., 2020). In April and May of 2020, the case rates for people with IDD increased by 2.5 times, compared to an increase of 1.6 times for the general population (Landes et al., 2020). The incidence proportion for the two groups increased at the same rate through July 2020, with the incidence of COVID-19 among people with IDD remaining significantly higher than for people without IDD (Landes et al., 2020). Similarly, while Landes et al. (2021b) found lower overall rates of COVID-19 diagnosis among service users with IDD, case rates were highest in settings with more residents.

## Theoretical Framework

Epistemic injustice, specifically hermeneutical injustice, will be used to understand the impact of COVID-19 and the resulting public health response on people with IDD (Fricker, 2007). Hermeneutical injustice refers to harm in the capacity of being known, or more frequently, in not being known (Fricker, 2007). The process of knowledge creation is rarely neutral or passive, but rather an active effort to maintain established power structures (Peña-Guzmán & Reynolds, 2019). This form of epistemic injustice is most clearly seen in the pervasive exclusion of people with IDD from public health research, health-related policy, and medical education.

In the context of the United States' response to the COVID-19 pandemic, hermeneutical injustice and its consequences are most obvious in the exclusion of people with IDD from public health research (Krahn, 2019; Magana, 2016). The need for better data is well established among disability researchers. One study suggested that national health surveillance surveys only identify about 60% of adults with IDD who live in the community (Magana et al., 2016). These surveys often lack disability identifiers, use broad language that does not distinguish between conditions like intellectual disability, developmental disability, dementia, and traumatic brain injury, or do not include people with IDD in their sampling frames (Havercamp et al., 2019; Krahn, 2019). Additionally, definitions of IDD differ and may be based on diagnoses or functional limitations, making it difficult to make comparisons across surveys or data collection systems (Krahn, 2019).

Hermeneutical injustice is a form of powerlessness and structural discrimination which, beyond the abstract harms of being excluded from knowledge creation, leads to tangible social injustices (Dore, 2019; Fricker, 2007). When not critically examined, the underlying assumptions about less powerful groups, including people with IDD, become integrated into policy without consideration for the harm they may cause (Dore, 2019; Weibgen, 2004). Hermeneutical injustice thus provides a useful framework for unpacking these assumptions to better understand the marginalization and discrimination faced by people with IDD during the COVID-19 pandemic in the United States.

### Research Questions

This study aims to better understand the impact of COVID-19 on people with IDD using publicly available public health data and a representative sample of state-funded service users with IDD. Specifically, the paper seeks to answer the following questions:

1). To what extent did states explicitly protect people with IDD in their COVID-19 response, including emergency response and treatment rationing plans?

2). How did differences in state responses impact reported COVID-19 infection for people with IDD?

## Methods

## Ethical Oversight

This study was reviewed and approved by the institutional review board at the author's affiliated university.

## Data

### NCI-IPS

The National Core Indicators project is a collaboration between the National Association of State Directors of Developmental Disability Services (NASDDDS), the Human Services Research Institute (HSRI), and participating states to measure a variety of outcomes (employment, community participation, rights and choices, etc.) for people with IDD who use state funded service (NASDDDS & HSRI, n.d.). The project is intended to track these performance and outcome measures over time, make comparisons between states, and establish national benchmarks for tracking service quality (NASDDDS & HSRI, n.d.). The NCI-IPS is a face-to-face interview of adults with IDD who use at least one state-funded disability service in addition to case management. Participants are randomly selected from each participating states' population of IDD service users. Participating states must achieve a sufficient sample to allow for comparisons between states with at least a 95% confidence interval. Generally, a sample of 400 people meets this threshold; many states oversample for a variety of reasons.

The NCI-IPS consists of three sections. The background section contains information regarding the participant's disability diagnosis, health conditions, service usage, and support needs and is generally completed by a case manager prior to the interview. Section I of the survey is a series of subjective questions about a participant's quality of life and satisfaction with services which can only be answered directly by the individual with IDD. Finally, Section II consists of objective questions about the participant's rights, choice-making, and community participation. Section II may be completed by a respondent with IDD or by someone who knows them well. All variables for this paper came from the background section of the NCI-IPS.

Data for this paper came from the 2020-2021 data collection cycle. The outcome of interest for this analysis was whether the participant had been diagnosed with COVID-19. This variable came from the background section of the NCI-IPS, which is completed by a case manager prior to the face-to-face interview. Specifically, this item asked whether the participant had ever been “diagnosed or presumed diagnosed with COVID-19,” defined as having received a positive test result for COVID-19, been told by a physician that they had COVID-19, or shown signs and symptoms consistent with COVID-19). Only affirmative (“yes”) and negative (“no”) responses were included in the analysis; “don’t know” responses were counted as missing data.

### State COVID-19 Response

Federal guidance from the CDC and the White House COVID-19 response team was used to evaluate state responses to the COVID-19 pandemic in early 2020. This paper focused on guidelines issued between January and July 2020 to align with data collection for the NCI-IPS, analysis for state crisis standards of care plans (described in the next section), and key decisions in the federal response to COVID-19.

The CDC first issued advice against gatherings of 50 or more people on March 12, 2020 (CDC.org, 2020a). This guidance was immediately followed by recommendations from the White House COVID-19 on March 16, 2020. The “30 Days to Slow the Spread" campaign recommended that people work or attend school from home when possible and avoid gatherings of more than 10 people, unnecessary travel and social visits, eating at bars and restaurants, and visiting nursing homes and other long-term care facilities (trumpwhitehouse.archives.org, 2020).

Some states and territories responded by issuing stay-at-home orders to enforce these guidelines, beginning with Puerto Rico on March 15 and California on March 19, 2020 (Moreland et al., 2020). These policies were evaluated based on their timing and concordance with federal recommendations, based on the data gathered by Moreland and colleagues (2020). States that issued a universal, mandatory stay-at-home order were scored as 2, those that issued an advisory or a mandate that only applied to some people were scored as 1, and those that did not issue guidance were scored as 0. States where some counties issued stay-at-home orders were still scored as 0, reflecting the lack of state-wide guidance.

The CDC first officially recommended that all Americans wear a cloth face mask “in public settings where other social distancing measures are difficult to maintain” on April 3, 2020 (cdc.org, 2020b). This recommendation was followed by state mandates beginning with New Jersey on April 10, 2020, and New York on April 15, 2020 (ballotpedia.org, 2022). The CDC issued a stronger call for Americans to wear a face mask outside of their home on July 14, 2020, based on emerging evidence for masking as an important tool in preventing the spread of COVID-19 (cdc.org, 2020c). State mask policies were compiled by Ballotopedia (2022). States that implemented a mask mandate in the first half of 2020 (prior to June 1) were scored as 2, those that implemented a mandate after June 1, 2020 were scored as 1, and states that never issued guidance on masking were scored as 0. Again, only state-wide policies, not county-level guidance, were considered in this scoring.

## State Disability Response

In addition to states’ overall response to the COVID-19 pandemic, this paper also measured the extent to which these responses explicitly protected people with IDD.

### Crisis Standards of Care Plans.

Crisis Standards of Care (CSOC) plans are guidelines for alterations to usual healthcare that may be made during emergency situations in which resources are limited (Institute of Medicine [IOM], 2009). In the United States, many of these plans were developed in response to the 2009 H1N1 pandemic and have come under increased scrutiny during the COVID-19 pandemic, particularly for their treatment of disability (Cleveland Manchada et al., 2021; Ne'eman et al., 2021). While CSOC plans are intended to outline an equitable distribution of resources, many plans discriminated against people with disabilities and other chronic health conditions in their prioritization guidelines, especially early in the COVID-19 pandemic (CPR, 2020a; Guidry-Grimes et al., 2020; Ne'eman et al., 2021).

This paper evaluated CSOC plans based on guidelines suggested by the Center for Public Representation (2020b) in collaboration with partner organizations. CSOC plans were identified from a dashboard compiled by the Center for Public Representation (2020a), and through reviews by Cleveland Manchada and colleagues (2021) and Ne'eman and colleagues (2021). When none of these sources had a link to a state's plan we searched for "[state name] crisis standards of care plan" or "[state name] COVID-19 allocation plan" on Google and on the state's health department website. Finally, as some states had updated their CSOC plan during the COVID-19 pandemic, we utilized the Internet Archive (archive.org, n.d.) to identify the plan on record in early 2020 to coincide with the timeframe of the NCI-IPS data. The evaluation criteria and scoring criteria are presented in Table 1. Scores were calculated by totaling a state's points for each criterion. States without a CSOC plan were not included in the analysis.

### COVID-19 Impact

Cumulative COVID-19 case and death rates for each state as of August 1, 2020, were used as a measure of the impact of the pandemic. Daily case and death counts for each state were compiled by the CDC (data.cdc.gov, n.d.); each state's census data (United States Census Bureau, 2022) were used to calculate rates per 100,000.

### Analysis

Multilevel modeling was used to account for clustering of individuals within states to explore inter-state variability in COVID-19 diagnosis. Specifically, generalized linear mixed modeling was used as all variables were categorical. Analysis was conducted in R (R Core Team, 2017) using the lme4 package (Bates et al., 2015). The null model consisted of the outcome variable (COVID-19 diagnosis) and the cluster variable (state). Model 1 added individual level predictors and Model 2 added the state level predictor. Because not every state had a CSOC plan on file, Model 2 was run with and without CSOC scores as a predictor.

The level two (state-level) predictor variable was the state COVID-19 response score. The COVID-19 response score includes both the state's disability response and their general response to the pandemic. As described previously, the disability response score includes elements of state CSOC plans scored using an evaluation framework suggested by disability advocacy organizations (CPR, 2020b). The general response score includes state closing, stay at home, and masking mandates, analyzed based on their concordance with federal guidelines.

## Results

### Participants

Sample characteristics are presented in Table 1. Respondents came from 26 states, with a total sample of 19,991. However, rates of missingness for COVID-19 diagnosis were very high, with only 10,093 valid responses after excluding missing data and "don't know" responses. Additionally, these patterns of missingness were not spread equally among the states, with four states accounting for 9,095 of the missing or "don't know" responses. The 10,093 cases with valid responses to COVID-19 diagnosis were used as the sample for all analyses. The implications of the high rates of missingness will be addressed more thoroughly in the discussion section. Of the remaining sample, 10.77% (1087) had been diagnosed with COVID-19.

## State Responses

### State COVID-19 Policies.

Masking and stay-at-home guidelines were identified for all 50 states and ranged from 0 to 2, with higher scores indicating stricter COVID-19 policies. The average score for masking policies was 1.06, while the average score for stay-at-home policies was 1.56.

### CSOC Plans.

CSOC plans with specific allocation criteria published prior to June 1, 2020, were identified for 24 states, of which 13 participated in the NCI-IPS. Of these states, scores ranged from 3 to 14 with an average score of 7.54. Nationally, scores ranged from 3 to 14 with an average score of 7.86. Higher scores indicated closer compliance with the CPR evaluation framework.

### State COVID-19 Impact.

Of the states that participated in the NCI, cases per 100,000 ranged from 15.2 to 2466.91, with an average of 1,122.75. Nationally, cases rates ranged from 15.12 to 14,132 and averaged 1,487.28. Among states who participated in the NCI, deaths per 100,000 ranged from .66 to 170.59 and averaged 33.47. Comparatively, death rates in all states ranged from .66 to 344.75 and averaged 44.34.

## Bivariate Relationships

Significant associations of being diagnosed with COVID-19 were found at the individual and state levels and are presented in Table 3.

### *Individual Level*

Respondents in the youngest age category (18-29) were less likely to have been diagnosed with COVID-19, while those in the oldest two categories (50-64 and 65+) were more likely to have been diagnosed ($X^2(4) = 35.55$, $p < .001$). Several chronic health conditions were significantly associated with decreased likelihood of being diagnosed with COVID-19 including dysphagia ($X^2(1) = 8.22$, $p = .004$), a cardiovascular condition ($X^2$ (1), 5.78, $p = .016$), high cholesterol ($X^2$ (1) = 12.61, $p < .001$) and high blood pressure ($X^2$ (1) = 6.50, $p = .01$). People with autism were more likely to have been diagnosed with COVID-19 than people without autism ($X^2$ (1) = 6.50, $p = .01$). Notably, while Down Syndrome was often prioritized as a high-risk condition, it was not significantly associated with having a diagnosis of COVID-19.

The ways respondents interacted with their community were also associated with the likelihood of being diagnosed with COVID-19. Residence was significantly associated with diagnosis, with people who lived in an Intermediate Care Facility (ICF), nursing home, or other institution or group home setting being more likely to have been diagnosed and people who lived with family or in host homes being less likely to have contracted COVID-19 ($X^2$ (7) = 317.79, $p < .001$). Having a day activity in the community was also associated with an increased likelihood of diagnosis ($X^2$ (1) = 32.72, $p < .001$). Having a job was not significantly associated with COVID-19 diagnosis in the bivariate analysis but became significant in the regression models.

### *State Level*

At the state level, the degree to which a state responded to the COVID-19 pandemic was significantly associated with COVID-19 diagnosis. People who lived in states that had stricter stay at home ($t(10091) = 3.18$, $p < .001$) and masking guidelines ($t(10091) = 4.70$, $p < .001$) were less likely to have been diagnosed with COVID-19. The overall prevalence and impact of

COVID-19 was also significantly associated with COVID-19 diagnosis. People who lived in states with higher case rates (t(10091) = -7.06, p < .001) and death rates (t(10091) = -2.01, p = .04) were more likely to have been diagnosed with COVID-19. The degree to which states issued explicit protections for people with disabilities in their CSOC plans had borderline significance (t(4820) = 1.77, p = .07). Participants who had been diagnosed with COVID-19 were more likely to live in states with higher scores on their CSOC plans.

## Multilevel Model

### *Intraclass Correlation (ICC) and Model Fit*

To assess the appropriateness of multilevel modeling, the intraclass correlation (ICC) was calculated by dividing the group variance (Level 2) by the total variance (Levels 1 and 2). An ICC of .05 or greater suggests that multilevel models should be used (Garson, 2019). In the Null Model the ICC was .10, indicating that approximately 10% of the variance in COVID-19 diagnosis occurs at the state level.

A two-level logistic regression was fitted with COVID-19 diagnosis as the dependent variable. The Null Model only included the cluster variable, state, as a predictor. Model 1 included all individual predictors and Model 2 added the state-level predictors. These results are presented in Table 4.

Two measures of model fit--the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC)--were used to assess the predictive power of more complex models (Garson, 2019). Of the 26 states with NCI-IPS data, 13 states had CSOC plans. Because not every state had a CSOC plan, the state-level model was run with and without this variable. The state-level model with CSOC included had higher predictive power and so was retained as the final model.

Both the AIC and BIC in each model decreased with the addition of predictors, indicating that variables at the individual and state levels added significant predictive power to the model.

In the final model, a person’s residence remained the strongest predictor of their likelihood of being diagnosed with COVID-19. Compared to people who lived in an intermediate care facility (ICF), nursing home, or other facility, those who lived in their own home (OR -1.27, p = .02) or with family (OR -2.28, p < .001) had lower odds of having been diagnosed with COVID-19. At the state level, people who lived in states with higher rates of COVID-19 had higher odds of diagnosis (OR .51, p = .001) while people who lived in states with higher death rates had lower odds of diagnosis (OR -.29, p = .02).

## Discussion

Hermeneutical injustice offers a framework for understanding how ableism and other forms of discrimination shape decisions around who and what are known. In a global health emergency like COVID-19, who is known often directly translates to who is prioritized in the public health response. As such, this paper highlights the ways in which COVID-19 exacerbated existing health inequities for people with IDD, including in hermeneutical injustices from discrepancies in public health data. It also underscores the ways in which federal and state policies interact with individual- and system-level factors to impact a person’s risk during a public health emergency.

This analysis supports the literature that suggests that people with IDD may have a higher risk of contracting COVID-19 than the general population (Gleason et al., 2021). While cases per 100,000 as of August 1, 2020, averaged 1,122.75 (1.12%) in states that participated in this NCI-IPS (data.cdc.gov, n.d.), approximately 10% of the sample reported being diagnosed with COVID-19 during the same timeframe. Given the evidence that people with IDD who contract

COVID-19 are at an increased risk of severe outcomes compared to people without IDD, understanding these risks is imperative to develop an equitable response to future public health emergencies.

Like previous research, this study suggests that where people with IDD lived significantly impacted their risk of contracting COVID-19. In the final model, people who lived in intermediate care facilities, nursing homes, or other institutional settings had significantly higher odds of being diagnosed with COVID-19 compared to people who lived independently or with family. In the bivariate analysis, all congregate settings (ICF/nursing home, 2-3 person group homes, 4-6 person group homes, and 7-11 person group homes) were associated with higher than expected rates of COVID-19 diagnosis. In contrast, living with family or in a host home was associated with lower than expected rates of being diagnosed with the virus.

Given the history of institutionalization for people with IDD, understanding the risks associated with living in congregate settings is particularly important. In 2017, 220,895 people, approximately 26% of people with IDD who used state-funded Long-Term Services and Supports (LTSS) lived in a group setting, which some researchers suggest may represent 13-20% of people with IDD (Larson et al., 2020; Shapiro, 2020). In contrast, only about 6% of people over 65 live in congregate settings (Shapiro, 2020). People who live in group settings face a number of factors that increase their risk of being exposed to COVID-19. Sharing a home with multiple people may make physical distancing difficult or impossible (Landes et al., 2021b).

Additionally, especially in the first months of the COVID-19 pandemic, direct support professionals (DSPs) who worked in group homes often lacked appropriate personal protective equipment (PPE; Shapiro, 2020). DSPs may also be more likely to contract and spread COVID-19; low wages mean that many DSPs work in multiple settings and often rely on public transportation (Pettingell et al., 2023; Shapiro, 2020). This risk is reflected by other studies on inequities in the COVID-19 response, which suggest that social distancing was weaker and risk of exposure to COVID-19 was higher in areas with higher concentrations of poverty and essential workers compared to more affluent areas where more people were able to work from home (Garnier et al., 2021; Gwynn, 20201).

It is also possible, however, that after the initial delay in guidance, people who lived in congregate care settings were tested for COVID-19 more frequently than people who lived on their own or with family. Research from before the COVID-19 pandemic suggested that people with IDD who lived in congregate care settings were more likely to have received recommended preventative care than people who lived independently or with family (Bershadsky et al., 2012). The challenges of accessing healthcare in the community may have been exacerbated by the reliance on drive-through and mass testing sites, which were often inaccessible for people with disabilities (Epstein et al., 2021). While the NCI-IPS included symptoms associated with COVID-19 in their question about diagnosis, asymptomatic or mild cases may have been missed in some settings.

Geographically, where people lived was also significantly associated with their risk of being diagnosed with COVID-19. As expected, people who lived in states with higher case rates of COVID-19 were significantly more likely to have been diagnosed with the virus. Living in a state with a higher death rate was also associated with participants' odds of being diagnosed with COVID-19, but not in the expected direction; higher state death rates were significantly related to lower odds of being diagnosed. It is possible that high death rates in these states made the dangers of the virus more salient, so that people took more individual precautions to protect themselves. More research is needed to better understand this dynamic.

Furthermore, while they were not significant in the final model, state-level responses (masking and stay-at-home mandates) to COVID-19 were significantly associated with a person's odds of being diagnosed with the virus in the bivariate analysis. Additionally, these factors were associated with a state's case and death rates, which were associated with the odds of COVID-19 diagnosis in the final model. Additional research is needed to understand these relationships between state policy, COVID-19 cases and deaths, and individual outcomes.

## Implications for Health Equity

This study also underscores the importance of hermeneutical justice for an equitable public health response, as well as how repeated injustices can build upon each other to perpetuate inequity. Monitoring the incidence and outcomes of COVID-19 for people with IDD was limited by a lack of health data that long predated the pandemic (Havercamp et al., 2019; Krahn, 2019). This absence of baseline knowledge was then compounded by insufficient testing (Bergquist et al., 2020; Xu & Basu, 2020) that did not collect disability data (Berquist et al., 2020), and was often inaccessible to people with disabilities (Epstein et al., 2021). Research on outcomes for patients who contracted COVID-19 was similarly limited, as most secondary data analysis relied on diagnostic codes in a patient's medical chart to identify an intellectual and/or developmental disability (Gleason et al., 2021). Combined, these persistent exclusions from research and knowledge creation culminated in a situation in which the needs of people with IDD were often overlooked.

The consequences of hermeneutical injustice for people with IDD continued past the initial wave of COVID-19 in the US. Vaccination against COVID-19 was not considered in this study because vaccines were only beginning to be authorized at the time of the NCI-IPS survey. However, the COVID-19 vaccine rollout in the US is a key example of why disability data is necessary for an equitable public health response. While people living in congregate care settings, including group homes for people with IDD, and people with some specific conditions, including Down Syndrome, were prioritized early (Hotez et al., 2021), a review conducted in early 2021 found that only 10 states prioritized people with other physical, intellectual, and/or developmental disabilities (Jain et al., 2021). This deprioritization can be partially attributed to the lack of data about health outcomes for people with IDD and other disabilities (Hotez et al., 2021; Wiggins et al., 2021). In this way, hermeneutical injustice–the exclusion of people with IDD from research–negatively impacts the health outcomes for people with IDD in a public health emergency.

## Limitations

This analysis was limited by high rates of missing data. As reported previously, only about half of the sample had a valid response for the NCI-IPS question about COVID-19 diagnosis, with four states accounting for over 90% of the missing responses. It is worth noting that rates of missing data for COVID-19 diagnosis were similar to rates for other health-related variables, which may suggest a limitation with the survey data. While the differences were somewhat less dramatic than for data related to COVID-19, the missingness for other health conditions was not distributed evenly across states, with very high missingness for some states in the sample. It is possible that some interviewers skip non-applicable questions in the background section of the NCI-IPS instead of answering in the negative.

Additionally, inconsistencies in states’ responses to COVID-19 made comparison challenging. Specifically, only about half of the states with NCI-IPS data had a CSOC plan on record. While CSOC scores added predictive power to the model and were retained, additional research is needed to better understand the impacts of having specific, state-level protections for people with disabilities in a public health crisis. Furthermore, while data on COVID-19 case rates and death rates were available for each state in this analysis, the validity of this data is dependent on coordinated testing and reporting. Evidence suggests that these numbers may be underreported (Xu & Basu, 2020), especially for nursing homes and congregate care settings (Berquist et al., 2020).

These limitations with the data coupled with the timing of the NCI-IPS data meant that the analysis in this paper focused on odds of being diagnosed with COVID-19 as an outcome of interest. As described previously, people with IDD are also at increased risk for severe illness, hospitalization, and death following infection with COVID-19 (Clarke et al., 2020; Fair Health, 2020; Gleason et al., 2021; Landes et al., 2020; Landes et al., 2021; Spreat et al., n.d.). Additionally, there is increasing evidence for negative psychosocial outcomes including mental illness, behavioral support needs, and isolation (see Carey et al., 2022; Fisher et al., 2022; Friedman, 2021). Future research should consider the range of impacts that the COVID-19 pandemic has had on people with IDD.

## Conclusion

These findings suggest that individual-, system-, and state-level factors are all associated with a person's risk of contracting COVID-19, so that a successful public health response must consider the broader context in which a person lives. These factors are particularly important for people with IDD, who interact with the environment in ways that may put them at increased risk from contracting COVID-19 and for poor outcomes compared to people without disabilities. Unfortunately, historic and ongoing hermeneutical injustice means that these factors are not well understood and, as such, not considered in public health decisions. Pursuing health equity and hermeneutical justice requires actively including people with IDD in public health research in preparation for future emergencies and natural disasters.

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20BETWEEN%20%272020-08-01T00%3A00%3A00%27%20%3A%3A%20floating_timestamp%0A%20%20%20%20AND%20%272020-08-01T00%3A00%3A00%27%20%3A%3A%20floating_timestamp%0AORDER%20BY%20%60state%60%20ASC%20NULL%20LAST/page/aggregate

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# Tables

**Table 1.** *CSOC Scoring Criteria*

| Variable | Definition | Scoring |
|---|---|---|
| Equity | Allocation plan explicitly states and defines equity/fairness as a principle of the framework. | 0 = no plan<br>1 = equity is stated, not defined<br>2 = equity is stated and defined |
| Identity Statement | Allocation plan explicitly prohibits discrimination based on race, disability, and other protected classes. | 0 = no statement<br>1 = some classes are stated<br>2= statement includes disability, race, and other major protected classes |
| Reasonable Modification | Assessment criteria allows for modification to account for pre-existing disabilities. | 0 = no<br>1 = yes |
| Eligibility | Plan explicitly states that all patients are eligible for life-saving treatment. | 0 = no<br>1 = yes |
| Resource Intensity | Plan allows for consideration of expected intensity/continued need for resources (ex. home oxygen use) | 0 = considers resource intensity<br>1 = resource intensity not mentioned<br>2 = consideration for resource intensity/ongoing need is explicitly prohibited |
| Categorical Exclusion | Plan explicitly prohibits categorical exclusions based on diagnosis | 0 = plan categorically excludes patients with some diagnoses<br>1 = no categorical exclusions<br>2 = plan explicitly prohibits categorical exclusions |
| Survival | Allocation plan explicitly states that treatment decisions should be based on likelihood of surviving the acute illness | 0 = long term survival (>2 years)<br>1 = medium term survival (6 months - 1 year)<br>2 = short term survival (acute illness period) |
| Reallocation | Reallocation plan is specified and allows for extended time as reasonable accommodation | 0 = no reallocation plan is specified<br>1 = reallocation plan is defined, no reasonable accommodation<br>2 = reallocation plan specifies extended time as accommodation |

| | | |
|---|---|---|
| Personal Ventilators | Plan includes protections for personal ventilators | 0 = no<br>1 = yes |
| Appeals process | Plan includes an appeals process for patients denied treatment | 0 = no<br>1 = yes |

**Table 2.** Predictors of COVID-19 Diagnosis

| | Valid % | N |
|---|---|---|
| COVID-19 Diagnosis (N = 10,093) | | |
| Yes | 10.77 | 9006 |
| No | 89.23 | 1087 |
| Age (N = 19,912) | | |
| 18-29 | 28.30 | 5635 |
| 30-39 | 25.34 | 5045 |
| 40-49 | 15.48 | 3082 |
| 50-64 | 21.48 | 4278 |
| 65+ | 9.40 | 1872 |
| Race (N = 18,026) | | |
| Black | 14.30 | 2752 |
| Latino | 16.67 | 3207 |
| White | 60.61 | 11661 |
| Other | 2.08 | 406 |
| Gender (N = 19,872) | | |
| Female | 41.01 | 8150 |
| Male | 58.99 | 11722 |
| Health Conditions | | |
| Cardiovascular (N = 10,632) | 6.69 | 712 |
| Diabetes (N = 10,716) | 12.71 | 1362 |
| Cancer (N = 10,702) | 2.35 | 252 |
| High Blood Pressure (N = 10,594) | 21.48 | 2276 |
| High Cholesterol (N = 10,556) | 18.56 | 1959 |
| Dysphagia (N = 10,688) | 8.36 | 894 |
| Level of ID (N = 16,679) | | |
| Mild | 40.76 | 6799 |
| Moderate | 29.67 | 4949 |
| Severe | 13.71 | 2286 |
| Profound | 7.95 | 1326 |
| Unspecified | 7.91 | 1319 |
| Down Syndrome (N = 11,252) | 9.34 | 1051 |
| Autism (N = 19,495) | 22.62 | 4410 |
| Residence Type | | |
| ICF/Nursing Home | 5.17 | 1019 |
| Group Home 2-3 | 8.23 | 1624 |
| Group Home 4-6 | 19.22 | 3790 |
| Group Home 7-11 | 2.62 | 516 |
| Own Home | 15.70 | 3097 |
| With Family | 42.71 | 8424 |
| Host Home | 5.93 | 1171 |
| Other | .42 | 83 |
| Day Activity (N = 12,528) | 44.87 | 5621 |
| Job (N=12,531) | 23.07 | 2891 |
| State Level | | |
| | N | Mean (SD) |
| CSOC (N = 13,896) | | 9.06 (2.51) |
| Masks | 19,991 | 1.04 (.52) |
| Stay-at-Home | 19,991 | 1.79 (.50) |
| Case Rates | 19,991 | 1134.48 (465.50) |
| Death Rates | 19,991 | 28.20 (25.01) |

**Table 3.** Bivariate Associations with COVID-19 Diagnosis

| | $X^2$ (df) |
|---|---|
| Age | 35.52 (4) *** |
| Black | .74 (1) |
| Latino | 1.22 (1) |
| White | 3.18 (1) |
| Other | 2.44 (1) |
| Gender | .47 (1) |
| Cardiovascular | 5.78 (1) * |
| Diabetes | 3.39 (1) |
| Cancer | .35 (1) |
| High Blood Pressure | 6.5 (1) * |
| High Cholesterol | 12.62 (1) *** |
| Dysphagia | 8.22 (1) ** |
| Level of ID | 10.05 (4) * |
| Down Syndrome | .09 (1) |
| Autism | 6.50 (1) * |
| Residence Type | 317.79 (7) *** |
| Day Activity | 32.72 (1) *** |
| Job | .26 (1) |
| | t (df) |
| CSOC | 2.23 (4475) * |
| Stay Home | 3.32 (9746) *** |
| Masks | 5.10 (9746) *** |
| Cases | -3.23 (9386) ** |
| Deaths | -3.03 (9386) ** |

* p < .05 ** p < .005 *** p < .001

**Table 4.** Multilevel Model

| Odds Ratio (Standard Error) | Null Model | Model 1 | Model 2 |
|---|---|---|---|
| Intercept | -2.24 ** (.13) | -1.03 (.35) ** | -1.19 (.96) |
| Age (30-39) | | .13 (.14) | .12 (.21) |
| Age (40-49) | | -.15 (.17) | -.47 (.26) |
| Age (50-64) | | -.12 (.16) | -.15 (.23) |
| Age (65+) | | -.25 (.22) | -.24 (.32) |
| Race (Black) | | -.07 (.130 | -.03 (.19) |
| Race (Latino) | | .07 (.25) | .25 (.31) |
| Race (Other) | | -.36 (.37) | -.86 (1.06) |
| Cardiovascular disease | | .10 (.20) | -.02 (.29) |
| Cancer | | -.21 (.32) | -.09 (.46) |
| Diabetes | | .15 (.14) | .18 (.20) |
| High Blood Pressure | | -.12 (.13) | -.23 (.19) |
| High Cholesterol | | .03 (.13) | .23 (.19) |
| Dysphagia | | .18 (.24) | .11 (.38) |
| Moderate ID | | .07 (.11) | .14 (.16) |
| Severe ID | | -.59 (.27)* | -.23 (.36) |
| Profound ID | | -.72 (.53) | -.75 (.77) |
| Unspecified ID | | .03 (.210 | .13 (.35) |
| Down Syndrome | | 0.10 (.19) | .37 (.29) |
| Autism | | -.10 (.14) | -.25 (.24) |
| Group Home 2-3 | | -1.22 (.34)*** | -1.32 (.57) * |
| Group Home 4-6 | | -.83 (.33)** | -1.04 (.58) # |
| Group Home 7-11 | | -.47 (.37) | -.20 (.65) |
| Own Home | | -1.33 (.33)*** | -1.35 (.57) * |
| With Family | | -2.02 (.33)*** | -2.36 (.58) *** |
| Host Home | | -1.48 (.36)*** | -1.16 (.61) # |
| Other Residence | | -2.32 (1.06)* | -14.30 (536.55) |
| Job | | .31 (.12) ** | .15 (.18) |
| Day Activity | | .32 (.11)** | .13 (.15) |
| CSOC | | | -.04 (.04) |
| Masks | | | .42 (.30) |
| Stay-at-Home | | | .21 (.30) |
| Case Rate | | | .51 (.16) *** |
| Death Rate | | | -.28 (.13) * |

* p < .05 ** p < .005 *** p < .001

# Chapter 5

# Discussion and Conclusion

## Discussion

Like most disasters, the COVID-19 pandemic has exposed underlying disparities and disproportionately impacted historically marginalized communities (Gusmano et al., 2020; Weibgen, 2014). People with intellectual and developmental disabilities (IDD) may have been at particular risk for contracting COVID-19 and for negative physical health outcomes from the virus compared to people without disabilities (Davis et al., 2021; Gleason et al., 2021; Karpur et al., 2021; Koyoma et al., 2022; Landes et al., 2020; Landes et al., 2021a; Landes et al, 2021b; Landes et al., 2021c; Malle et al., 2021; Turk et al., 2020). Additionally, people with IDD faced significant disruptions to services, fewer opportunities to participate in community activities, and increased worry, anxiety, and mental health symptoms (Carey et al., 2022; Fisher et al., 2022; Friedman, 2021; Hartley et al., 2022; Linehan et al., 2022; Rosencrans et al., 2021).

This dissertation sought to examine the impact of COVID-19 on people with intellectual and developmental disabilities (IDD) through the framework of epistemic injustice (Fricker, 2007). Paper one provides a theoretical grounding for the secondary data analyses of papers two and three by applying the principles of epistemic injustice to a scoping review of the literature about COVID-19 and people with IDD. Paper two builds on the understanding of testimonial injustice gained from Paper one to examine how people with IDD have been included in research on COVID-19. This paper used exploratory graph analysis (EGA; Golino & Epskamp, 2017) to examine the impact of COVID-19 as measured by the COVID-19 Supplement of the National Core Indicators In-Person Survey. Finally, paper three focuses on hermeneutical injustice to understand how the exclusion from research, specifically large-scale public health data, affected the ways in which people with IDD were included in state responses to COVID-19.

Findings from this dissertation study add to the existing research documenting both the physical and psychosocial impacts of COVID-19 on people with IDD as well as how people with IDD have been largely excluded from this research. Both the scoping review from paper one and the secondary data analysis in paper three support previous findings that people with IDD are at an increased risk of contracting COVID-19 compared to people without disabilities and that a person's residence is a crucial factor to consider in understanding their risk of exposure to the virus. Paper two adds to the body of research documenting the perceived impacts of COVID-19 on services, community participation, and wellbeing for people with IDD.

Additionally, papers two and three build on the framework of epistemic injustice established in paper one to examine how the experiences of people with IDD in the COVID-19 pandemic have been understood and researched. Paper two uses the concept of testimonial injustice and focuses on the methodological, epistemic, and moral implications of using proxy-responses in survey research with people with IDD. Paper three uses hermeneutical injustice to examine the implications of a lack of data about health outcomes for people with IDD, highlighting the ways that this absence may have contributed to COVID-19 mitigation efforts that did not center their needs and the consequences of this exclusion.

## Strengths and Limitations

To my knowledge, this dissertation was the first time epistemic injustice has been used to understand the experiences of people with IDD during the COVID-19 pandemic in the United States. While some disability scholars have criticized the theory of epistemic injustice for narrowly conceptualizing knowledge and communication in ways that exclude people with IDD

(Catala et al., 2020), it remains a useful framework for interrogating the moral, intellectual, and practical harms of being excluded from research.

Papers two and three of this dissertation used the National Core Indicators In-Person Survey (NCI-IPS). There are strengths and limitations to using this data source. The NCI-IPS is a random sample of people with IDD who use state-funded services; participating states are required to achieve a large enough sample to allow for comparisons between states and over time. However, literature suggests that surveys of service users may only reach 60% of people with IDD living in the community (Magana et al., 2016). Additionally, there were high rates of missingness for variables related to COVID-19 in the NCI-IPS, which limited analyses.

## Conclusions and Implications

Despite these limitations, this dissertation has several important implications for understanding the impact of COVID-19 on people with IDD as well as for equity in research and health moving forward. Findings from this dissertation suggest that researchers in the IDD field must explore ways to make their work more inclusive of people with IDD. In designing research projects, paper two supports previous literature that suggests that proxy-responses to survey questions cannot fully replace self-report, so that researchers must find ways to make their projects more accessible for people with IDD.

At a larger scale, paper three highlights the ways in which a lack of data can negatively impact health outcomes for people with IDD. Ongoing work is needed to include disability identifiers in population-level survey data and to ensure that these surveys reach people with IDD so that data is available to inform future public health decisions.

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# Vita

## Sarah Lineberry, MSW, LCSW

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## EDUCATION

Virginia Commonwealth University — Richmond, VA
School of Social Work PhD Program — Expected March 2023
Doctor of Philosophy
Dissertation: Impact of COVID-19 on Adults with Intellectual and Developmental Disabilities in the United States

University of North Carolina at Chapel Hill School of Social Work — Chapel Hill, NC
School of Social Work — May 2016
Master of Social Work
Nonprofit Leadership Certificate
Fellowship: Leadership Education in Neurodevelopmental Disabilities program at the Carolina Institute for Developmental Disabilities. Funded by the U.S. Maternal and Child Health Bureau.

University of North Carolina at Chapel Hill — Chapel Hill, NC
Bachelor of Science in Psychology with a Bachelor of Arts in Spanish — May 2013
Minor in Anthropology

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## INTERESTS

### Research

Intellectual and Developmental Disabilities
Social Determinants of Health
Community Integration
Quality of Life and Wellbeing

### Teaching

Social Work Research Methods
Human Behavior in the Social Environment
Social Welfare Policy
Disability Policy & Services

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## RESEARCH EXPERIENCE

*Program Evaluation Associate* (2023-Present)
Virginia Partnership for People with Disabilities

*Costs and Outcomes for People with Intellectual and Developmental Disabilities Who Use Services in Virginia* (2019 - Present)
Virginia Partnership for People with Disabilities
Funding Source: National Institute on Disability, Independent Living, and Rehabilitation Research
Role: Research assistant
Co-PIs: Matthew Bogenschutz, Parthenia Dinora

*Exploring COVID-19 Vaccine Confidence and Uptake Among People with Intellectual and Developmental Disabilities and Their Families* (Summer- Fall 2021)
Virginia Partnership for People with Disabilities
Funding Source: Virginia Department of Behavioral Health and Developmental Services
Role: PI

*Voting and Disenfranchisement Among Adults with Intellectual and Developmental Disabilities* (Summer - Fall 2020)
Virginia Commonwealth School of Social Work
Role: PI

*Center for Dignity in Healthcare for People with Disabilities* (February 2021-Present)
*Cincinnati Children's Hospital Medical Center, University of Cincinnati, Cincinnati, OH*
Role: Workgroup member
Duties: Serve on a taskforce addressing inequities in COVID-19 treatment and vaccination plans. Summarized existing data on increased risk from COVID-19 for people with IDD for health departments and disability advocacy organizations for presentation at the White House Taskforce on COVID-19.

*Consumer Directed Services Survey* (Summer 2022)
*Virginia Board for People with Disabilities, Richmond, VA*
Role: Data Analyst
Duties: Conducted descriptive and bivariate analyses on a survey of consumer-directed service users. Presented results in narrative and visual formats suitable for distribution in agency report.

***LEND Trainee*** 2015-2016
*University of North Carolina at Chapel Hill - Chapel Hill, NC*

Designed an IRB-approved study to examine barriers to healthcare for individuals with intellectual and developmental disabilities. Conducted qualitative interviews on healthcare access with individuals with IDD, their family members, and healthcare providers to identify barriers and potential solutions to improve healthcare access for patients with complex medical needs**.**

## SOCIAL WORK PRACTICE EXPERIENCE

***COVID-19 Response Team Member*** May 2020 - Present

*Richmond City Health District - Richmond, VA*

Serve in a variety of roles to support COVID-19 testing, vaccination, and education efforts in the community. Progressed from Medical Reserve Corps volunteer to contracted employee on the COVID-19 response team. Provide remote and on-site data management support for registration at testing and vaccine events, including the Doses on Demand program for in-home vaccination. Work with RCHD leadership to ensure an equitable distribution of services in Richmond City and Henrico County.

***Director of Professional Services*** 2016-2019

*L'Arche Chicago - Chicago, IL*

Oversaw developmental and implementation of services for adults with intellectual and developmental disabilities, including monitoring state and federal benefits, ensuring compliance with state regulations, coordinating mental and physical healthcare, and providing supervision for counselors, behavioral therapists, and nurses working with residents. Supported other leadership staff in supervising and managing live-in and live-out assistants from a range of racial, cultural, and linguistic backgrounds.

***Manager*** June 2016-September 2016

*Extraordinary Ventures - Chapel Hill, NC*

Managed small businesses employing individuals with IDD. Coordinated and supervised employees and job coaches.

***Program Associate/Intern*** 2015-2016

*The Arc of North Carolina - Raleigh, NC*

Attended meetings at the North Carolina General Assembly with The Arc's advocacy team. Conducted policy research and analysis to inform stakeholders on IDD policy. Collaborated with Easter Seals UCP to implement the North Carolina Council on Developmental Disabilities' Medical Health Home initiative

***Direct Support Professional*** 2015-2016

*The Arc of the Triangle - Chapel Hill, NC*

Supported individuals with IDD at home and in the community. Coordinated with individuals and their families to plan and implement goals.

***Live-In House Assistant*** 2013-2014

*L'Arche Edinburgh - Edinburgh, Scotland, UK*

Lived with and supported adults with developmental disabilities in an integrated community setting**.** Worked with assistants from a variety of cultural, linguistic, and professional backgrounds

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## GRANTS

***Identifying Predictors of Enhanced Outcomes for People with Intellectual and Developmental Disabilities.*** (Funded).
National Institute on Disability, Independent Living, and Rehabilitation Research ($600,000)
Role: Co-Investigator
Years of Funding: 2019-2021

***Longitudinally Measuring Personal and Health Outcomes for People with IDD who use Medicaid HCBS.*** (Funded).
National Institute on Disability, Independent Living, and Rehabilitation Research ($600,000)
Role: Co-Investigator
Years of Funding: 2021-2023

***COVID-19 Response Grant.*** (Funded).
Virginia Department of Behavioral Health and Developmental Services.
Role: Co-Investigator
Years of Funding: 2021

***Systems for Action: Supplemental Research on COVID-19 Response and Recovery for People with Intellectual and Developmental Disabilities.*** (Not funded).
Robert Wood Johnson Foundation.
Role: Co-Investigator

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## PEER REVIEWED JOURNAL PUBLICATIONS

### Published and In Press

**Lineberry, S.,** Bogenschutz, M., Broda, M., Dinora, P., Prohn, S., & West, A. (In press). Co-occurring mental illness and behavioral support needs in adults with intellectual and developmental disabilities. *Community Mental Health Journal.* https://doi.org/10.1007/s10597-023-01091-4

**Lineberry, S.,** Bogenschutz, M., Dinora, P., & Ayers, K. (2023). The role of information and knowledge in COVID-19 vaccination among people with intellectual and developmental disabilities and their families. *Intellectual and Developmental Disabilities, 61*(1), 16-30. https://doi.org/10.1352/1934-9556-61.1.16

Dinora, P., Prohn, S., Bogenschutz, M., Broda, M., **Lineberry, S.**, & West, A. (2023). An examination of support needs, supports, and outcomes for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 61*(1), 65-78. https://doi.org/10.1352/1934-9556-61.1.65

**Lineberry, S.,** Bogenschutz, M. (in press). Voting and disenfranchisement among people with intellectual and developmental disabilities. *Journal of the Society for Social Work and Research.* Preprint available: https://doi.org/10.1086/717/59.

Broda, M., Bogenschutz, M., **Lineberry, S.,** Dinora, P., Prohn, S., & West, A. (accepted) Employment and employment goals in a matched sample of people with intellectual and developmental disabilities with and without autism. *Journal of Vocational Rehabilitation.*

Bogenschutz, M., Dinora, P., **Lineberry, S.**, Prohn, S., Broda, M., & West, A. (2022). Promising practices in the frontiers of quality outcomes measurement for intellectual and developmental disability services. *Frontiers in Rehabilitation Sciences: Disability, Rehabilitation, and Inclusion*, e871178. http://doi.org/10.3389/fresc.2022.871178.

Prohn, S., Dinora, P., M. Broda. M., Bogenschutz, M., & **Lineberry, S.** (2022). Measuring four personal opportunities for adults with intellectual and developmental disabilities. *Inclusion, 10*(1), 19-34. https://doi.org/10.1352/2326-6988-10.1.19.

Broda, M., Bogenschutz, M., Dinora, P., Prohn, S., **Lineberry, S.** & Ross, E. (2021). Using machine learning to predict patterns of employment and day program participation. *American Journal on Intellectual and Developmental Disabilities, 126*(6), 477-491). http://doi.org/10.1352/1944-7558-126.6.477*.*

Bogenschutz, M., Broda, M., **Lineberry, S.**, & Prohn, S. (2021). Testing a wellness indicators measure for people with intellectual and developmental disabilities. *Developmental Disabilities Network Journal, 2*(1), 85-103. https://digitalcommons.usu.edu/ddnj/vol2/iss1/9/

**Under Review**

**Lineberry, S.**, & Bogenschutz, M. Applying a disability equity framework to state crisis standards of care plans.

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**PRESENTATIONS**

**Peer Reviewed Presentations**

**Lineberry, S.**, West, A ., Dinora, P., Prohn, S., Bogenschutz, M**.**, &, Broda, M. (2022, November). *A Model for Partnering with People with Intellectual and Developmental Disabilities to Develop and Conduct IDD Outcomes Research.* Oral presentation for the Association of University Centers on Disability Annual Conference: Washington, DC.

**Lineberry, S.**, Bogenschutz, M**.**, Dinora, P., Prohn, S., Broda, M., & West, A. (2022, June). *Mental health, behavioral support needs, and personal outcomes for adults with IDD.* Presented to the Annual Conference of the American Association on Intellectual and Developmental Disabilities: Online.

**Lineberry, S.** (2022, April). *COVID-19 Vaccine Confidence and Uptake Among People with Intellectual and Developmental Disabilities and Their Families.* Poster presentation for the Virginia Commonwealth University Graduate Research Symposium.

**Lineberry, S.,** Bogenschutz, M., Broda, M., Dinora, P., & Prohn, S. (2022, January). *The Impact of Mental Health Diagnosis and Behavioral Support Needs on Personal Opportunity Outcomes for Adults with Intellectual and Developmental Disabilities.* Oral presentation for the Society for Social Work and Research 26th Annual Conference: Washington, DC. (Withdrawn due to COVID-19)

**Lineberry, S.**, Bogenschutz, M. (2021, June). *Factors Associated With Voting in Adults With Intellectual and Developmental Disabilities Receiving Services in Virginia.* Poster presentation for the American Association on Intellectual and Developmental Disabilities 145th Annual Meeting. [virtual].

Bogenschutz, M., Dinora, P., **Lineberry, S.**, Prohn, S., & Broda, M. (2021, June). *Relationships between support needs, service use, and personal outcomes for people who use developmental disability waiver services in Virginia.* Paper presented to American Association on Intellectual and Developmental Disabilities Annual Conference: Online.

Bogenschutz, M., Dinora, P., Prohn, S., **Lineberry, S.**, & Broda, M. (2021, November). *Using Machine Learning to Predict Employment and Day Activity Outcomes for People with IDD.* Poster presented to the Association of University Centers on Disability Annual Conference: Online.

Dinora, P., Broda, M., **Bogenschutz, M.,** Prohn, S., & **Lineberry, S.** (2020, December). *Using merged datasets to predict personal outcomes for people who use developmental disability waiver services in Virginia*. Poster presented to the Association of University Centers on Disability Annual Conference: Online.

**Lineberry, S.,** Bogenschutz, M. (2020, December). *Understanding the Barriers and Facilitators to Voting for People with Intellectual and Developmental Disabilities.* Poster presentation for the American Association of University Centers for Excellence in Developmental Disabilities Annual Conference. [virtual].

### Invited Presentations

Bogenschutz, M. & **Lineberry, S.**. (2021, April). Mental health, behavioral support needs, and personal outcomes for people with intellectual and developmental disabilities. Presented to Psychiatry Grand Rounds, VCU School of Medicine: Richmond, VA.

**Lineberry, S**. & Bogenschutz, M**.**, (2021, April). Mental health, behavioral support needs, and personal outcomes for people with intellectual and developmental disabilities. Recorded for the InterHab Power Up Conference: Wichita, KS. Available at: https://interhab.org/2022-conference-materials/

### Community Presentations

Riddle, I., Griffen, A., Iadarola, S., Siegal, J., Bonuck, K., Siasoco, V., **Lineberry, S.**, Smith, L., Hall-Lande, J., & Shaffert, R. (2021, November). COVID-19 Pandemic and Beyond: What's Next? Fireside chat presented by the AUCD Health and Disability Special Interest Group.

**Lineberry, S.,** Harris, S., Copeland, M., & Boyd, J. (2020, August). Decision 2020: Why the disability vote matters. Facebook Live Webinar presented to the Center on Disability Leadership and the Center for Family Involvement. Available at: https://www.facebook.com/centerfordisabilityleadership.cdl/videos/3216521921766480

Brandt, J., Rogers, R., Bogenschutz, B., **Lineberry, S.**, & Tranyham, D. (2020, July). Virginia 2020 Elections Info Session. Virtual meeting hosted by the Virginia Partnership for People with Disabilities.

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## TRANSLATIONAL DISSEMINATION

**Lineberry, S.,** Bogenschutz, M., Dinora, P., & Ayers, K. *The role of information and knowledge in COVID-19 vaccination among people with intellectual and developmental disabilities and their families.* Graphic prepared for distribution to accompany manuscript preprint.

**Lineberry, S.,** Bogenschutz, M., Dinora, P., & Ayers, K. *Who's had the vaccine? Understanding COVID-19 vaccine confidence for people with IDD and their families.* Graphic distributed via the Center for Family Involvement. Available at: https://www.facebook.com/CenterforFamilyInvolvement/photos/4191260444335845

**Lineberry, S.,** Bogenschutz, M., Dinora, P., & Ayers, K. *Vaccines for children under 12: Understanding COVID-19 vaccine confidence for people with IDD and their families.* Graphic distributed via the Center for Family Involvement and the Center for Disability Leadership. Available at: https://www.facebook.com/CenterforFamilyInvolvement/photos/?ref=page_internal

**Lineberry, S.,** & Bogenschutz, M. (2020, August). *Your vote counts.* Graphic distributed via the Center on Disability Leadership. Available at: https://www.facebook.com/centerfordisabilityleadership.cdl/photos/a.119290933140816/170180711385171/

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## AWARDS & Scholarships

***Champion of Accessibility*** 2021
VCU Transforming Accessibility Initiative

Virginia Commonwealth University's highest award to recognize faculty, staff, and students who demonstrate exemplary dedication to improving access and inclusion for community members with disabilities and/or chronic illness.

***Hans Falck Doctoral Scholarship*** 2022
Virginia Commonwealth University
Award amount: $850

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## TEACHING

*Lead Instructor* Fall 2022
Virginia Commonwealth University
Course: SLWK 601, Human Behavior in the Social Environment
Program: Master of Social Work

*Lead Instructor* Summer 2022
Virginia Commonwealth University
Course: SLWK 609, Foundations of Research Methods
Program: Master of Social Work, online

*Co-Instructor* Fall 2021
Virginia Commonwealth University
Course: SLWK 603, Power, Privilege, and Oppression

Instructor: Hollee McGinnis, PhD
Program: Master of Social Work

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## SERVICE

### To Virginia Commonwealth University

***Provost's Graduate Students Advisory Council*** 2022

### To the VCU School of Social Work

***PhD Student Representative***

Search Committee for Assistant Dean for Student Affairs and Inclusive Excellence 2022

Governance and Operations Committee 2022-2023

***Peer Mentor***

| | |
|---|---|
| 2020-2021 | PhD Student |
| 2021-2022 | PhD Student |

### To the Partnership for People with Disabilities

***COVID-19 Response Task Force*** 2020-2021

### To the Community

***Virginia Medical Reserve Corp*** May 2020-Present

***Board Member, L'Arche Metro Richmond*** July 2020-Present

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## PROFESSIONAL AFFILIATIONS

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| Society for Social Work and Research | 2019-Present |
| American Association on Intellectual and Developmental Disabilities | 2019-Present |
| Association of University Centers on Disability | 2019-Present |